

From dying with dignity to living with rules

- AIDS treatment and 'holistic care' in Catholic organisations in Uganda

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Louise Mubanda Rasmussen

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From dying with dignity to living with rules: AIDS treatment and 'holistic care' in Catholic organisations in Uganda

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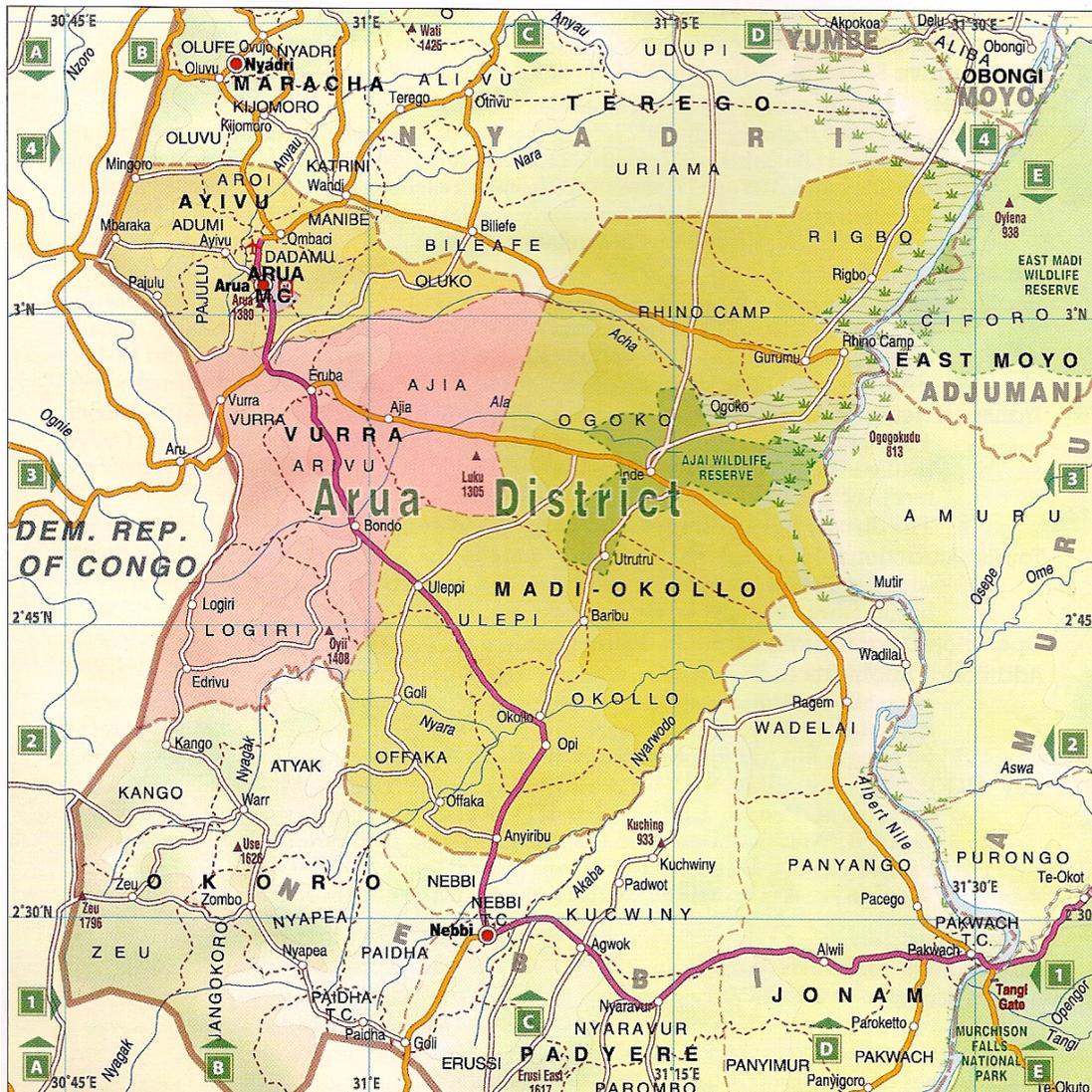
Thank you – webale nyo – awa'difo saru!

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Map of Arua district



From: Uganda Districts Information Handbook – Expanded Edition 2007-2008. Fountain Publishers, Kampala.

1. Introduction

This dissertation is a study of three Catholic organisations in Uganda involved in providing ‘treatment, care and support’ to people living with HIV/AIDS. One is an NGO operating under the auspices of Kampala Archdiocese. The two others operate under Arua Diocese (in the Northwestern corner of Uganda), and include an AIDS clinic in a Catholic hospital and a home-based care programme coordinated by a Catholic health centre.

With the term ‘treatment, care and support’ I am referring to a governmental field where divergent conceptions of how to combine bio-medical treatment, spiritual or emotional care and social support to people living with HIV/AIDS, are negotiated and transformed.

In this dissertation, I combine Foucault-inspired theoretical insights with ethnographic studies to explore the intersections between the three Catholic organisations’ religious ideals and practices, ‘global AIDS treatment’ and the self-government the organisations attempt to promote among people living with HIV/AIDS. I conclude the dissertation with an analysis that point towards the ways in which people with HIV/AIDS attempt to realise the potentials of these self-government techniques and AIDS treatment in their everyday lives. The dissertation argues that the effects of these practices of AIDS treatment and ‘holistic care’ include producing new life-prolonging potentials, but also new uncertainties and inequalities.

The dissertation is placed within two contemporary developments in relation to the AIDS epidemic in Sub-Saharan Africa. One is the dramatically rapid ‘roll-out’ of antiretroviral (ARV) treatment, which has taken place in many countries across the continent since 2004. The other is the increasing political and scholarly interest in the role of religious organisations in development generally, and in responding to the AIDS epidemic in Sub-Saharan Africa, specifically. By focusing on Catholic organisations, this dissertation contributes with new perspectives to the discussions on AIDS & Religion in Africa, which have been dominated by a focus on Pentecostal churches. In relation to the scale-up of ARV treatment, studying Catholic organisations serves as an exemplary case, which brings to light central dilemmas that the provision of ARV treatment is faced with in Sub-Saharan Africa.

Scaling-up ARV treatment in Sub-Saharan Africa

From the late 1990s, a transnational advocacy coalition lobbying for greater access to ARV treatment in development countries began to take shape (Wogart 2007; Nguyen 2005). By successfully framing limited access to AIDS treatment as a humanitarian emergency, activists managed to push for an unprecedented allocation of resources to make ‘universal access’ to ARV treatment possible (Nguyen 2009a). In 2002-3 large funding initiatives were initiated with this aim; The Global Fund to Fight AIDS, Tuberculosis and Malaria in 2002, and in 2003 the US President’s Emergency Plan for AIDS Relief (PEPFAR), and WHO and UNAIDS’s 3 by 5 initiative. Subsequently, highly reliant on donor funding, many African countries have ‘scaled-up’ the access to ARV treatment in the last five years. In Uganda, it was estimated that about 10,000 people were taking ARV treatment in 2003, the majority paid for the drugs themselves (Meinert et al. 2003). Recently, the US ambassador in Uganda proudly reported in a Ugandan newspaper the US’ contribution¹ in raising the numbers of people accessing ARV treatment in Uganda to 218,000 (Lanier 2010). Currently, the Ugandan government’s official goal is to have 240,000 people with access to ARV treatment by 2012, constituting 80% of those who need the treatment (Uganda AIDS Commission 2008: viii-ix).

With this increasing access to ARV treatment in Uganda, most Ugandans living with HIV/AIDS “no longer think of themselves as heading towards a certain death, but as being on a path of uncertain survival” (Meinert et al. 2009: 196). A growing number of critical studies of the ARV treatment scale-up in different African countries illustrate that there is a need to critically examine the political, social and governance-related implications of the framing of AIDS treatment as a humanitarian emergency along with the massive deployment of resources and medical technology, not the least to explore the possibilities as well as paradoxes this creates for people living with HIV/AIDS. This dissertation first of all takes the precaution that the provision of these ‘life-saving drugs’ in Uganda necessarily takes shape in political and social landscapes of inequality (Richey & Haakonsson 2004; Meinert et al. 2003), and therefore may reproduce or create inequalities.

Observing how consortia of NGOs, foreign donor governments, Northern universities and hospitals and even the American military are involved in mass AIDS treatment programmes in African countries, Nguyen proposes the hypothesis that these programmes constitute a kind of government-by-

¹ PEPFAR funds a large share of the AIDS treatment programmes in Uganda. According to Lanier, 184,000 Ugandan ARV patients are “directly supported by the American people” (2010).

exception; “a novel form of legitimate, therapeutic domination that results from framing the epidemic as a humanitarian emergency” (Nguyen 2009a: 196). Studies exploring the implications of AIDS treatment programmes from the point of view of people living with HIV/AIDS have shed light on the disconnections and dilemmas of this government-by-exception. Both Kalofonos (2008) and Seckinelgin (2008) focus on the dehumanizing effects of AIDS treatment programmes that solely focus on and target the medical experiences of people living with HIV/AIDS, since this focus does not capture in full the lived experiences of people living with HIV/AIDS (Seckinelgin 2008:1) and more broadly obscures the political and economic conditions of suffering (Kalofonos 2008). Based on studies in Uganda, Meinert, Mogensen and Twebaze (2009) argue that medical technologies and objectifications may in fact be appropriated by people living with HIV/AIDS to make sense of social life, but in ways that acutely illustrate social differences and inequalities.

In this dissertation, I take a slightly different approach. I study three Catholic organisations in Kampala and Arua as lenses through which to explore the implications of how ‘global AIDS treatment’ is currently practiced and debated. I focus on how the governmental and medical technology of ARV treatment is ‘translated’ in these Catholic organisations and by their employees and in turn how these ‘translations’ have implications for how people living with HIV/AIDS can and do realise the potential and promises of the technology in their own lives.

AIDS & Religion in Africa

Almost simultaneously with the scale-up of ARV treatment, questions around religion and AIDS in Africa began to interest policy makers and scholars alike. The academic debates on AIDS & Religion in Africa initially focused on local experiences of AIDS as crises of health, morality, sexuality and gender relations (cf. Setel 1999). The research focused on how religious practices and personal faith were harnessed to respond to such crises (Becker & Geissler 2007:2; Smith 2004; Becker 2007; Behrend 2007; Dilger 2007; Prince 2007). This dissertation is, however, placed within more recent research, which focuses on religious organisations’ involvement in the evolving institutional landscape of global AIDS treatment (e.g. Dilger 2009; Burchardt 2009; Patterson 2010; Leusenkamp 2010), situated in the shift “from the past times of the unstoppable virus into the equally complex and contested era of ART” (Becker & Geissler 2007: 13).

During the 2000s an increasing number of religious organisations, framed as ‘faith-based organisations’, became involved in AIDS interventions in Sub-Saharan Africa (Prince et al. 2009). In Uganda, as in other African

countries, especially PEPFAR's funding priorities provided new opportunities for faith-based organisations to grow and expand. The increasing involvement of religious organisations in AIDS interventions is part of a larger trend in which development agencies have begun to actively involve religious organisations in development work. Illustrated for example by the World Faiths Development Dialogue initiated by the World Bank and the Archbishop of Canterbury in the late 1990s (see Marshall and van Saanen 2007).

The possible positive contributions of religious organisations to the AIDS response began to be considered in international policy circles from the early 2000s. In relation to HIV prevention, the views on religious organisations tend to be polarised between proponents of abstinence and faithfulness campaigns and proponents of condom use and sex education (e.g. E. Green 2003; Epstein 2007). Especially with regards to the Catholic Church, the condom question has been extremely controversial (e.g. Lewis 2009). However, when it comes to the possible contributions of religious organisations providing 'treatment, care and support' to people living with HIV/AIDS, the views are usually less polarised (Prince et al. 2009: x). Supposedly, representing 'indigenous' forms of community organising to provide consolation and support through networks of compassionate volunteer work (cf. Nguyen 2005: 127), religious organisations have been seen to offer something unique and different from government interventions (Dilger 2001). Also, because home-based care organised within mainline Christian churches in fact constitutes one of the earliest responses to the AIDS epidemic in different African countries (Iliffe 2006; Prince et al. 2009; Blinkhoff et al. 1999).

In Uganda, two Catholic organisations were, along with The AIDS Support Organisation (TASO)², among some of the first initiatives to place community-based and home-based care on the agenda in the late 1980s. One of these is the Catholic NGO, Kamwokya Christian Caring Community (KCCC), which is one of the three organisations studied in this dissertation. KCCC and a number of similar Catholic NGOs in Kampala initially formulated their responses to AIDS as a matter of providing 'holistic care'. They promoted a view on the suffering brought about by AIDS as tied into larger social and spiritual issues, so that 'healing' required a holistic combination of social, medical, economic and spiritual interventions (see also Czerny 2007; Katongole 2007).

² TASO was started in 1987 and is widely recognised as the first organised group of people living with HIV/AIDS in Africa. It has since grown to become a nation-wide NGO, which is internationally renowned, see <http://www.tasouganda.org/>

Currently, in the context of the ARV treatment scale-up, religious ‘community-based’ organisations hold promises for overcoming some of the sustainability and cost-effective concerns of making ARV treatment widely accessible in African countries. With their framing of holistic HIV/AIDS care, they could also potentially bridge the gap between lived experience of HIV/AIDS in African countries with the solely medical focus of AIDS treatment programmes as outlined by e.g. Kalofonos (2008) and Seckinelgin (2008). However, as this dissertation argues, the engagement with global AIDS treatment may reconfigure the rationalities around ‘holistic care’, shifting them towards a more medicalised and individualised view on suffering and healing.

The AIDS response in Museveni’s Uganda

With HIV prevalence rates hovering around 10%-20% in the early 1990s, which by 2002 had declined to around 5% (Parkhurst 2005), Uganda is one of the very few success stories in Sub-Saharan Africa in terms of halting the spread of HIV/AIDS. Uganda and President Museveni has attracted much international attention and recognition for this achievement. Today, the HIV prevalence seemed to have stabilised around 5-6% (UNAIDS 2008a).

In recent years, the interpretations of the factors behind Uganda’s success have become highly politicised. The consequence of PEPFAR funding priorities for Ugandan AIDS policy were interpreted by some as a detrimental setback for the successful ABC strategy, because abstinence messages were now prioritised at the expense of condom promotion (e.g. Epstein 2007; Human Rights Watch 2005). PEPFAR proponents, however, argued that the focus on abstinence and faithfulness built exactly upon what had proven to be successful in Uganda (e.g. E. Green 2003).

What this debate tends to obscure is that religious organisations and particularly Christianized discourses have been part of ‘the Ugandan AIDS response’ from the onset. Though the flow of PEPFAR funding from 2004 gave new opportunities for both local and international Pentecostal involvement (Gusman 2009), the older mainline Christian churches (the Anglican and the Catholic Churches), as well as Muslim organisations, have been part of the ‘multisectoral’ response for a long time. In addition, the Ugandan government’s own AIDS campaigns have played on Christian moralities (Seidel 1990). In the early 1990s, Museveni pursued a ‘quiet promotion of condoms’ trying to pragmatically accommodate religious leaders’ opposing views on condom promotion (Parkhurst 2001: 78; O’Manique 2004: 147).

Generally, ‘non-governmental organisations’ have continuously played a crucial role in the institutional landscape around AIDS in Uganda. Many commentators point to the openness the Ugandan government practised towards both local and international NGO involvement (e.g. Allen & Heald 2004; Richey & Haakonson 2004). This openness is credited for producing a diversity of approaches and prevention messages (Parkhurst 2001), and preventing the alienation of religious groups experienced in other African countries (Allen & Heald 2004; cf. Pfeiffer 2003). Some scholars point out that the Ugandan government’s effort to create an ‘NGO friendly environment’ was a strategic and pragmatic response. When the National Resistance Movement (NRM) came to power in 1986, Uganda had witnessed almost two decades of armed conflicts and political chaos, and with a near-collapse of state infrastructure, the government was reliant on the older mission churches as well as newly emergent NGOs for basic service delivery (Parkhurst 2001; Seidel 1990; Swidler 2006: 280). The NGO friendly environment helped constitute Uganda as the country in the world receiving the highest amount of international funding for HIV/AIDS activities (Parkhurst 2005: 585). As a result of this flow of international funding, the number of AIDS-NGOs grew exponentially in Uganda during the 1990s (de Coninck 2004).

The Ugandan AIDS response can thus be seen to exemplify what Ferguson and Gupta has termed “transnational governmentality” (2002), particularly in the way service delivery was taken over by “a hodgepodge of transnational private voluntary organizations” (Ferguson 2006: 40). The distinctiveness of the Ugandan situation, however, being that Museveni successfully played this system to his own political advantage. Parkhurst argues that while the Ugandan government relied on churches, NGOs and the international community for service delivery, implementation and financing, it managed to insist on its role as coordinator of the national response. In this way, Museveni has been able to take credit for Uganda’s HIV/AIDS success and build legitimacy for his NRM government, internally and externally (Parkhurst 2005; Rau 2006: 291-2).

Another important context to the Ugandan AIDS response is the macro-economic policy context in which it was implemented (O’Manique 2004). After the NRM take-over in 1986, a project of economic recovery began, which largely followed the path of ‘structural adjustment’ (de Torrentè & Mwesigye 1999). The Ugandan government has been internationally praised for its adoption of structural adjustment programmes, and their apparent success was illustrated by economic growth rates just below 7% from 1987 to the late 1990s (Bigsten & Kayizzi-Mugerwa 1999: 3; 97). However, in recent years the economic success story has come under increasing domestic scrutiny (Tripp 2004). From 1997, the economic

growth started to slow down and at the same time income inequality began to rise (Okidi et al. 2007: 169), leading to a continuous concentration of wealth in urban centres and in the southern regions (Hickey 2005). Significant for the AIDS response is that the structural adjustment programmes have generally affected widespread privatization of health and social services delivery (cf. Bigsten & Kayizzi-Mugerwa 1999).

The three Catholic organisations studied in this dissertation operate in this context of growing inequality, general privatization of health and social service delivery, and the context outlined above of a high degree of involvement of local and international NGOs and faith-based organisations in the AIDS response.

Providing ARV treatment in Uganda

The provision of ARV treatment in Uganda is characterised by transnational links and by the general state of the health sector described as a ‘public-private mix-up’ (e.g. Whyte 2004 et al.). Institutions providing ‘free’³ ARV treatment include public health facilities, mission health facilities, and NGOs turned into AIDS clinics, all tied into transnational flows of funding and expertise. The largest provider is the former military research institution Joint Clinical Research Centre, which is primarily funded by PEPFAR (Richey & Haakonsson 2004).

The Catholic Church has provided health services in Uganda since the first Christian missionaries arrived in the late 19th century. During the political turmoil of the 1970s and early 1980s, Catholic as well as Anglican health facilities provided practically the only health service delivery in Uganda (de Torrentè & Mwesigye 1999: 18). Today, the Catholic health facilities together constitute the second largest health provider in Uganda (The governmental health sector is the largest health provider). Since 2004, the national project to scale-up ARV treatment has provided the Catholic health facilities with new opportunities and obligations to participate as providers of ARV treatment (Orach 2005).

Studying Catholic AIDS organisations in Uganda

The decision to focus on Catholic organisations was taken in the recognition that the research on AIDS and Religion in Africa has been dominated by a focus on new Pentecostal churches (see e.g. Smith 2004; Prince 2007; Dilger 2007; Sadgrove 2007). This trend also generally

³ I am referring here to programmes where the provision of ARV treatment is highly subsidized in contrast to private clinics where patients pay the full price for the medicine. In mission health facilities, patients often pay a (reduced) consultation fee to access services.

applies to the study of religion in Africa, where the mainline churches have been overlooked in the favour of Pentecostal churches and African Initiated churches (Meyer 2004; Maxwell 2006). In the Ugandan context, the two mainline churches, the Church of Uganda (Anglican) and the Roman Catholic Church, are crucial to the Ugandan AIDS response because of the way they have historically constituted a central duality in Ugandan religious, social and political life (Kassimir 1999; Gifford 1998; Ward 1995). In terms of membership, the two churches have been almost equal in numbers, with the Catholic Church having consistently slightly more members than the Anglican Church. According to available estimates Catholics constitute 40-45% and Anglicans 35-40% of the population⁴.

Since the political stability following the NRM takeover in 1986, the near-monopoly of the Anglican and the Catholic Church has, however, been shaken by a dramatic growth in new Pentecostal and other charismatic churches (Kassimir 1999). At the same time, Museveni's no-party system from 1986 to 2006 significantly reduced the political influence of the two political parties previously tied to the two mainline churches (Carbone 2008). The Uganda People Congress (UPC) was linked to the Anglican Church and the Democratic Party (DP) is still linked to the Catholic Church. Historically, the Church of Uganda has been more politically influential than the Catholic Church (Ward 1995), who on the other hand has been more involved in 'development' efforts, such as health and schooling, especially in rural areas (Gifford 1998).

My interest in the Catholic Church in Uganda lies in its strong position as a health care and social service provider. Additionally, studies that offer detailed, critical accounts of Catholic AIDS interventions in Africa are few (but see Joshua 2010), and largely overshadowed by the tendency to only consider the Catholic Church's contentious condom policies. This dissertation is partly motivated by the need to address this gap, including not taking for granted how condoms are dealt with in Catholic AIDS interventions.

The decision to focus on Catholic organisations was also connected to the fact that I already had a well-established contact with a Catholic NGO in Kampala. In 2006, I completed an internship and research for my master's thesis in Reach Out Mbuya⁵. My experiences in Reach Out had generated a

⁴ The 2002 national census recorded 42% Catholics and 36% Anglicans. The 1991 national census recorded 45% Catholics and 39% Anglicans. Islam constitutes a significant, though minor religious grouping with members amounting to 10-15% of the population. See <http://www.ubos.org/> (last accessed 7 Jan 2011).

⁵ Reach Out Mbuya Parish HIV/AIDS Initiative is an NGO initiated in 2001 by the Italian parish priest of Mbuya and a Danish doctor, along with a number of volunteers

general interest in the Catholic institutional landscape around AIDS interventions in Uganda. When I began fieldwork for this dissertation in March 2008, and started to explore what kind of Catholic AIDS projects to focus on, I became interested in a community-based organisation in Kampala, which is similar to Reach Out. This was the NGO Kamwokya Christian Caring Community (KCCC) mentioned above. I chose to focus on KCCC as a case illustrating a particular form of Catholic organisation, which is common in the Archdiocese of Kampala. However, I also wanted to include other types of Catholic engagements in the AIDS response and during the initial fieldwork I realised that studying AIDS interventions in ‘up-country’ dioceses could contribute another perspective.

Research in Kampala and Arua

The tendency in Uganda to refer to everywhere outside of Kampala as ‘up-country’, reflects how the capital of Kampala constitutes a political and economic centre, which is home to both the majority of the economic wealth and most of the international development economy (cf. Jones 2009: 9-10). Some of the different trajectories, dilemmas and experiences of AIDS projects in respectively the centre and in the margins of political and economic developments became apparent to me in the beginning of my fieldwork with Catholic national coordinating bodies.

In order to study an ‘up-country’ diocese, I chose to focus on Arua Diocese in the Northwestern corner of Uganda. This decision was tied to the marginal position this region has in Uganda – since early colonial conquests, the region has been spatially and politically marginalised (Leopold 2005). As a result of this marginalisation and its recent violent past, research on the region is scarce⁶. Therefore, choosing Arua Diocese could also serve the purpose of contributing something new to the overwhelming amount of research on AIDS in Uganda.

During my initial fieldwork in March-June 2008 of AIDS interventions in KCCC and Arua Diocese, questions around the ARV treatment scale-up were pervasive. I decided to focus this dissertation on ‘treatment, care and support’, to explore the different questions that AIDS treatment posed for community-based NGOs in Kampala and more resource constrained interventions in Arua Diocese.

who were caring for people seriously ill of AIDS. The organisation grew into a professional AIDS treatment organisation during the 2000s.

⁶Apart from Middleton’s classic ethnography of the Lugbara (e.g. Middleton 1965; 1971), some of the few recent studies on the region include studies on refugees and returnees (e.g. Harrel-Bond 1986; Allen 1996), and Leopold’s study of historical representations of the region’s marginality (Leopold 2005).

In Arua Diocese, I subsequently chose to focus on the only two organisations involved in providing treatment, care and support: an AIDS clinic in a rural Catholic hospital and a volunteer-driven home-based care programme coordinated by a Catholic health centre in Arua town. The word Catholic *organisations* is thus deliberately chosen to indicate that I do not analyse the Catholic Church in its entirety, but focus on three ‘religious development organisations’ connected to the Catholic Church (cf. Christiansen 2010). The three organisations function as cases illustrating different trends in Kampala Archdiocese and the ‘up-country’ diocese of Arua.

In the following sections, I present the three case organisations in detail and in their different geographical contexts.

Kampala Archdiocese: Kamwokya Christian Caring Community (KCCC)

Kampala Archdiocese, geographically covering the capital and two neighbouring districts, has historically constituted the centre of the Catholic Church in Uganda. Kamwokya Christian Caring Community is one among a number of Catholic community-based AIDS initiatives in the Archdiocese⁷.

KCCC is situated in the low-income, informal settlement called Kamwokya. The growth of densely built informal settings with poor infrastructure in Kampala is a testament to the rapid, but unequal economic growth Uganda has undergone in the last decades. Alongside the growth of such ‘slum’ areas⁸, Kampala is also home to a growing middle-class and is experiencing a rapid construction of new residential blocks, shopping malls and private hospitals.

Kamwokya is one of the oldest slum areas in Kampala; it began to grow in the 1970s and 1980s during the time of civil unrest and displacement (Wallman 1996: 1). Centrally located just to the northeast of the city centre and with a vibrant informal economy, Kamwokya is one of the most attractive slum areas in Kampala. As in other slum areas, the population in Kamwokya consists of an ethnically diverse mix of people, many of whom have migrated from other parts of the country in search of new opportunities for survival (Ibid: 17-46).

The Catholic parish Kamwokya was established in 1993, and prior to this it was a sub-parish under Mulago parish. Among the parishes in Kampala

⁷ Others include Reach Out Mbuya (started in 2001), Meeting Point (started in 1992) and Nsambya Home Care (started in 1987).

⁸ I use ‘slum’ area here, because it is the term often used by Kamwokya inhabitants to describe the settings of unplanned, densely built, low-quality houses with extremely limited water, sanitation and other infrastructure.

Archdiocese, Kamwokya stood out in the 1990s for its active Small Christian Communities and a lively Charismatic Renewal.

KCCC grew from the efforts of the Small Basic Christian Communities (known as *kabondo* in Luganda), whose members visited and helped sick and needy neighbours. These practices, which started around 1987, became linked to a new outreach programme to AIDS patients started by the Catholic, Nsambya hospital. This meant that the *kabondo* members' visits to 'the sick and needy' were transformed into functioning as links between the outreach team and AIDS patients. When three Franciscan Missionary Sisters for Africa moved to Kamwokya in 1990, they became involved in these initiatives, and a basic volunteer programme providing treatment and care to people with HIV/AIDS developed. Through this programme, volunteers gradually realised that the suffering around AIDS was often tied to larger social issues. In response to trying to meet the many related social, economic and spiritual needs of people living with HIV/AIDS, a wide range of interventions were initiated during the 1990s. These helped to constitute the organisation KCCC. The wide spectrum of medical, social, economic, spiritual and practical forms of help provided to people living with HIV/AIDS, along with HIV/AIDS prevention activities and support to orphans and vulnerable children, were defined as a 'holistic' approach to addressing HIV/AIDS.

In 1994, KCCC was registered with the Ministry of Internal Affairs as a faith-based NGO, under the authority of Kampala Archdiocese. In this way, KCCC is neither a classic lay organisation, a diocesan department or strictly a health facility. As an NGO, KCCC has, in similar ways to other Catholic-affiliated NGOs in Kampala, some degree of autonomy vis-à-vis the diocese. KCCC receives funding from a wide range of smaller donors consisting primarily of European and American faith-based organisations. At the time of my research, KCCC had about 140 full-time employees, and over 5,000 registered 'clients' (people living with HIV/AIDS) of which 1,500 were receiving ARV treatment.

KCCC began to provide ARV treatment in 2004 with the help of PEPFAR funding. As self-proclaimed pioneers in holistic HIV/AIDS care, the case of KCCC illustrates the ways in which Catholic community-based organisations' engagement in 'global AIDS treatment' pose new questions about the social and spiritual aspects of suffering and healing, and sustained social service delivery in the context of increasing 'NGOisation'.

Arua Diocese: Maracha Hospital and Ediofe Health Centre

Arua Diocese is situated in the Northwestern corner of Uganda, which lies to the west of the Albert Nile and borders DR Congo and Sudan. This area is also known as the West Nile region. Throughout the 1980s, 1990s and

early 2000s, the region was affected by instability and insurgencies⁹. With seemingly prevailing peace in neighbouring Northern Uganda and Southern Sudan, the region has for the first time in many years experienced a longer period of stability, at the same time as new development initiatives are coming their way. In the regional town of Arua, cross-border trade with Southern Sudan and DR Congo is one of the defining features. Arua town is also closely connected to a rural hinterland reliant on subsistence farming and growing tobacco as a cash crop (Leopold 2005: 34-43). According to the 2004-5 sero-behavioural survey, the West Nile region is the region in Uganda with the lowest HIV prevalence at 2,3% (Ministry of Health 2006: 103). It is probably fair to attribute part of this fact to the isolation of the region in the 1980s and 1990s when HIV was spreading rapidly in many other parts of Uganda.

Despite the previous marginalisation of West Nile, the region has in fact had the interest of international humanitarian agencies for decades (Leopold 2005; Allen 1996). This is connected to the region's proximity to Southern Sudan and due to the fact that the region has hosted the majority of the Sudanese refugees in Uganda. In Arua town today, UNHCR and Medicines Sans Frontières (MSF) constitute a visible presence. MSF has been instrumental in setting up a large AIDS programme at the Regional Referral Hospital in Arua, which in effect serves the whole region, including many patients from DR Congo and Southern Sudan. This AIDS programme has been providing ARV treatment since 2002.

However, apart from MSF's instrumental role in making the AIDS programme in Arua hospital possible, the humanitarian interventions in the region have mostly been geared towards the Sudanese refugees (Leopold 2005: 4; see e.g. Orach & de Brouwere 2006). The relatively greater resource constraints, compared to KCCC, which are faced by the Catholic health facilities in the region, reflects the uneven effects of the intersection between transnational NGO operations and Ugandan politics. In the context of these uneven effects, the Catholic Church constitutes a relatively resourceful institution in the region. The region noticeably has a relatively high proportion of Catholics, with 57% Catholics in Arua district (Arua District Census 2002¹⁰).

⁹ Known as the home area of Idi Amin, the region was the target of ethnically motivated retaliation after the overthrow of Amin in 1979. From the late 1980s to the end of the 1990s, two rebel fractions fought government forces. This conflict was in complicated ways intertwined with the conflict in Southern Sudan (Leopold 2005). In the first half of the 2000s, the Lord's Resistance Army targeted the outskirts of the West Nile region.

¹⁰ This census also covers today's Nyadri district where Maracha Hospital is situated. Nyadri district was carved out of Arua district in 2006.

In Arua Diocese, I have studied two cases: the AIDS clinic in Maracha Hospital and a home-based programme coordinated by Ediofe Health Centre. In this dissertation, these two cases illustrate treatment and care programmes operating under relatively greater resource constraints than in NGOs in Kampala. Specifically, Maracha Hospital represents a rural Catholic health facility's involvement in AIDS treatment. The programme coordinated by Ediofe Health Centre, which is situated in Arua town, illustrates a low-cost way of attempting to engage 'the community' in providing care and support to people living with HIV/AIDS.

The AIDS clinic in Maracha Hospital

St. Joseph's Hospital Maracha is situated 30 km. from Arua in a small trading centre called Ovujo. The hospital's catchment area, Maracha county, is a rural area, whose population rely on subsistence farming¹¹ and growing tobacco as a cash crop¹².

Maracha Hospital began to do HIV testing in 1998. In 2005 the hospital established an AIDS clinic. The clinic provides HIV counselling and testing, prevention of mother to child transmission, ARV treatment, prophylactic treatment and on-going counselling to people living with HIV/AIDS. The hospital, which has a bed capacity of 200, is generally challenged by a declining resource base and staff shortages (Maracha Hospital 2009). The AIDS clinic is partly supported by the government, as are some of the general operations of the hospital. The Ministry of Health's ARV programme provides the clinic with ARV treatment, septrin and testing kits. However, without much other outside funding, the AIDS clinic is severely resource constrained. Therefore, a user fee was introduced in September 2008 to cover the cost of running the clinic.

The clinic only has one permanent employee: a nurse-counsellor. When I visited the clinic in May 2008, there were two nurse-counsellors. But when I returned in March 2009, one of the nurses had been transferred to another ward, because of staff shortages in the hospital. Apart from the one nurse-counsellor, the clinic has four intern/volunteer counsellors, who are in charge of all the activities related to testing for HIV. The nurse-counsellor provides all the functions for people with HIV/AIDS ('clients'): on-going counselling, clinical consultation and drug dispensing. The clinic has 100-120 registered clients, which includes 60-70 clients receiving ARV treatment.

¹¹ Main food crops include cassava, millet, sorghum, ground nuts, beans and sweet potatoes.

¹² Tobacco cultivation is extremely labour intensive and identified as a major cause of hunger in the county (Maracha Hospital 2009: 13; Arua District Census 2002).

The hospital used to have some funding for ‘community activities’, which included home visiting and HIV/AIDS sensitisations conducted by the post-test club. But now that this funding has come to an end, these activities have more or less seized.

The home-based programme coordinated by Ediofe Health Centre

Ediofe Health Centre III is situated on the outskirts of Arua town in the Catholic mission in Ediofe. The home-based care programme began in 2004, when the health centre trained 25 people living with HIV/AIDS from all over Ayivu county, to function as ‘community counsellors’. This was made possible by the USAID-supported project AIDS Integrated Model District Programme. To date, these volunteers continue to conduct HIV/AIDS sensitisations and home-based care in the parishes where they live for a small token (which is provided by the Italian Comboni sister who is in charge of the health centre). The home-based care programme’s area of operation includes both Arua municipality and a surrounding rural area, which is similar to Maracha county, though in closer proximity to Arua town.

The volunteers visit between 5 to 10 clients in their homes in a month. The programme is somewhat unusual, since it is not directly linked to a treatment facility. The clients, the community counsellors visit do not receive their treatment from the health centre, but from the AIDS programme at Arua hospital. Consequently, the institution that provides ARVs and other medicines to the clients is not coordinating and monitoring these home-based care activities. This rather unique approach to home-based care, which is also quite different from the way home visits are organised in KCCC, constitutes an interesting case for investigating possible differences in terms of how ‘treatment, care and support’ is practised in Catholic organisations.

Analytical and methodological approach: Foucault-inspired ethnography

Following Foucault-inspired approaches to the study of international development and health, I study KCCC, Maracha Hospital’s AIDS clinic and the HBC programme coordinated by Ediofe Health Centre as *practices of government*, understood as specific institutional assemblages of governmental rationalities and technologies focused on how to shape the conduct of people living with HIV/AIDS.

One line of inquiry consists of exploring negotiations and tensions between different rationalities of government within the organisations. Here, I consider the importance of bio-political ambitions to ‘save lives’ with antiretroviral treatment and reduce HIV prevalence. I analyse how bio-

political ambitions are combined, negotiated or at odds with neo-liberal development rationalities and Catholic conceptions of ‘the good life’, both of which propose different questions of how people with HIV/AIDS should govern themselves.

I explore these tensions and negotiations by studying practices of counselling and home-based care, because these practices constitute sites in which questions of the conduct of people with HIV/AIDS are particularly relevant. Participant observations of counselling and home-based care in the three organisations, along with qualitative interviews, provide insights into how the governmental rationalities mentioned above are negotiated and translated in practice, including the divergent ways technologies and techniques may be taken up by counsellors and community workers. In the context of these ‘translations’, questions and dilemmas around the kind of self-government the organisations can and should develop among people living with HIV/AIDS become critical. Practices of ‘Positive Living’ constitute a central node around which ethical subject formation is negotiated with bio-political ambitions.

In the final chapter, I employ ethnographic perspectives on identities, socialities and possibilities for action, to analyse how people living with HIV/AIDS attempt to realise the potentials of these self-government techniques and the ARV medicine in their own lives. With these perspectives, I analyse the uneven ways people accept to become ‘clients’ in treatment programmes. I also explore the relevance of different socialities for the attempts of people living with HIV/AIDS to realise the life-prolonging potentials of ARV medicine and Positive Living practices in their own lives.

Concluding on the above, the research questions, which guide this dissertation, are:

How is ‘treatment, care and support’ for people with HIV/AIDS practised in KCCC, Maracha Hospital’s AIDS clinic and the Ediofe HBC programme, and what effects do these practices have on how people living with HIV/AIDS attempt to realise the life-prolonging potentials of ARV medicine and ‘Positive Living’ in their own lives?

Outline of the dissertation

In **chapter 2**, I introduce the analytical approach presented above, discussing the key theoretical concepts and questions informing this framework. **Chapter 3** provides an account of the methodological choices and challenges encountered during my fieldwork in Uganda. **Chapter 4** is a background chapter, which provides a brief history of the Catholic Church in Uganda, with a focus on Kampala and Arua dioceses. The chapter also includes a brief analysis of the politics and rationalities of ‘the Ugandan AIDS response’, considering the overall role played by the Catholic Church in Uganda.

In **chapter 5**, two of the rationalities of government most central in my analysis are introduced and analysed. These are the rationalities of holistic HIV/AIDS care, and the rationalities around the large-scale provision of antiretroviral treatment in Sub-Saharan Africa.

Chapter 6 provides an analysis of counselling practices in KCCC and the AIDS clinic in Maracha Hospital, focusing on how techniques of ‘Positive Living’ are used in counselling. The analysis illustrates dilemmas and tensions between bio-political ambitions on the one hand and on the other hand concerns with ethical self-practice, which result in transforming Positive Living practices along with ARV treatment requirements into ‘rules’ clients must follow.

In **chapter 7**, I analyse debates around nutritional and social support in the three organisations, in the context of the sustained ARV treatment scale-up. The chapter illustrates how the ideals of holistic care have come under pressure and how in the name of ‘sustainability’, a self-responsibilisation discourse is prevalent. This discourse places the responsibility for addressing social barriers to ARV treatment primarily on the clients and their families.

Chapter 8 provides an analysis of home-based care practices, focusing on KCCC and the HBC programme coordinated by Ediofe Health Centre. The chapter argues that with home visits, the organisations both aim to discipline clients to follow ‘the rules of ARVs’, and to produce responsible families and communities who can and will assist clients’ self-government. The chapter concludes with considering the position negotiated by the HIV positive volunteers conducting these home visits, analysing how they function as ‘Ambassadors of Positive Living’.

In **chapter 9**, I analyse the uneven ways people choose to become ‘clients’ in treatment programmes and openly take on an HIV positive identity. I also examine the relevance of different socialities for the attempts of

people living with HIV/AIDS to realise the life-prolonging potentials of ARV medicine and Positive Living practices in their own lives.

Chapter 10 is the dissertation's conclusion. Here, I conclude on what the negotiations between AIDS treatment and holistic care in the Catholic organisations illustrate more broadly about the global AIDS treatment regime and the dilemmas faced in expanding this treatment in contexts of inequality.

Appendix 1 is a table summarising information about the three Catholic organisations I have studied, which can be consulted while reading to ease the overview.

2. Analytical framework

This chapter introduces the theoretical questions that inform the analytical approach adopted in the dissertation. In the first section I draw upon a number of Foucault-inspired anthropological studies of global AIDS treatment (e.g. Nguyen 2005; Biehl 2007; Nguyen 2009a) and consider some of the Foucault-inspired theoretical insights to which these studies point. Under each of these analytical themes, I return to Foucault's own writings and also reflect upon how other studies of international development and health have employed these theoretical concepts. From these discussions, I develop the theoretical framework for the forthcoming analyses. In the final section, I discuss how to combine the Foucault-inspired framework with ethnographic approaches in order to move the analysis beyond the programmatic level, and focus especially on the effects of the programmes for people living with HIV/AIDS.

Bio-politics and biological citizenships

One of the recurrent analytical themes in studies of global AIDS treatment such as Nguyen (2005; 2009b) and Biehl (2007; 2008) is the question of bio-politics and forms of biological citizenship. Nguyen describes the transnational humanitarian assemblage concerned with 'saving lives' in Africa with ARV treatment, as an exercise of what Foucault termed 'bio-power'; "how sovereign rule is increasingly concerned with life itself, and how the exercise of bio-power requires the deployment of a range of technologies that target, describe and seek to regulate specific populations" (Nguyen 2009b: 199). Biehl generally refers to the pharmaceuticalisation of governance and citizenship – in this "philanthropic discourse, one saves lives by finding new technical tools and cost-effective means to deliver care; that is, medicines and testing kits en masse" (Biehl 2008: 103). Biehl thus points to the specific pharmaceutical orientation of the global bio-political concerns around AIDS.

In my reading of Foucault, one of the central points about bio-politics is that it is about optimising life by intervening at a general level of 'population' (Foucault 2003). Foucault points out that in contrast to disciplinary power that has individualising effects, by manipulating the individual body to render it useful and docile, bio-politics have totalising effects by directing itself towards life at the mass level of the population. Disciplinary power is applied to man-as-body, while bio-politics is applied

to man-as-living-being. Bio-power employs forms of knowledge such as statistics and forecasts in order to determine and describe specific populations (Foucault 2004: 246-9). With bio-politics we can point to how the AIDS epidemic is made known and intervened upon in terms of, for example, HIV prevalence rates, mortality rates, numbers of children orphaned by AIDS, and now, 'lives saved' with ARV treatment. Bio-politics also illustrates one of the ways in which the exercise of power can be productive, since it is "a power that exerts a positive influence on life, that endeavors to administer, optimize, and multiply it, subjecting it to precise control and comprehensive regulations" (Foucault 1978: 137).

Larsen argues that the bio-political concerns with optimising life, may be combined with concerns of 'governmentality': that is, how best to govern subjects. Therefore the politicisation of certain health problems may not necessarily only reflect a bio-political ambition to optimise life, but also a concern with how subjects govern themselves (Larsen 2011: 202-3). I use the concept of bio-politics to highlight how the three Catholic organisations are operating within 'a global moral economy' of bio-political reasoning in terms of 'saving lives' with ARV treatment (cf. Nguyen 2009a). But, especially, I use the perspective to analyse how biopolitical concerns and technologies (e.g. precise control and comprehensive regulations) are combined, negotiated or at odds with concerns of how people living with HIV/AIDS govern themselves.

Therapeutic citizenship

Based on concepts like biosociality and biological citizenship, Nguyen developed the now widely circulated term 'therapeutic citizenship' (2002; 2005). The term biosociality was first coined by Rabinow in relation to his discussion of new genetic technologies. He used the term to describe forms of collective identification and action formed around new biological categories and disease (Rabinow 1992). Rose and Novas argues that collective organising around specific biomedical categories are becoming increasingly significant, constituting new platforms for making claims for life and producing new kinds of biological citizenship (2005: 441-2).

Based on ethnographic studies in Burkina Faso and Côte d'Ivoire from the mid 1990s and onwards, Nguyen argues that earlier AIDS interventions paved the way for the emergence of new forms of therapeutic citizenship. Instigated by internationally-funded 'Greater involvement of people living with HIV/AIDS' projects, many self-help groups were formed and people increasingly took up the confessional technologies of speaking about their experiences of testing positive and living with HIV/AIDS. This helped constitute a kind of biosociality around AIDS: "the organisation of social relations according to a shared biological affliction" (2005: 131). This

biological ‘vanguard’ of individuals who had tested positive for HIV helped leverage the broad transnational advocacy coalition, which first contributed to the reduction in prices on ARV drugs (2005: 142) and later helped to push for the massive allocation of resources, which have made the ARV ‘scale-up’ possible in many African countries.

Thus, Nguyen argues that it was through the interplay between a global therapeutic economy (characterized by great inequalities in access to treatment), local tactics for mobilising resources, and the bio-political production of particular subjectivities that a kind of therapeutic citizenship emerged (2005: 142). Nguyen characterizes therapeutic citizenship as a form of stateless citizenship where claims are made on a global social order based on the therapeutic predicament of being HIV positive (Ibid: 126; 142). Therapeutic citizenship is not a matter of essentialised identity, but rather a system of claims and ethical projects (Ibid: 126). In discussing the Brazilian AIDS policy space, Biehl makes a similar point. In this space between international agencies, global markets and the reforming state, “mobilized individuals and groups must continuously maneuver this particular therapeutic formation to gain medical visibility and have their claims to life addressed” (2008: 105).

The notion of therapeutic citizenship has been taken up by a number of studies on AIDS treatment in Africa (e.g. Robbins 2008; Richey 2011; Blystad & Moland 2009). Based on research in Mozambique, Kalofonos argues that therapeutic citizenship constitutes “an incomplete, degraded form of belonging” (2008:18), illustrating the negative sides of a form of citizenship based solely on therapeutic predicament and access to medicines, in settings of inequality and scarcity. With reference to the Ugandan setting, Meinert et al. have pointed to the shortcomings of the concept in terms of foregrounding notions of individual rights and social activism at the expense of other kinds of socialities, which may be equally central or more important to access ARV treatment and stay alive (Meinert et al. 2009: 206; also Mattes 2009 on Tanzania). Generally, therapeutic citizenship was particularly well suited to discuss the proliferation of transnational activism around access to AIDS treatment, often with people living with HIV/AIDS at the forefront, in the first half of the 2000s. But now with the access to ARV treatment significantly ‘scaled-up’ in many African countries, new questions emerge about how ‘ordinary’ people living with HIV/AIDS translate the life-prolonging potentials of ARV medicine in their own lives, as well as how the local institutions rationalise and practice the governing of AIDS treatment.

As Nguyen points out, claims to therapeutic citizenship must be “worked out in the context of local moral economies” (2005: 142). Prior to the ARV treatment scale-up, this process was characterised by forms of social triage

in Burkina Faso (Ibid: 132) and in Uganda (Whyte et al. 2004). I use the concept of therapeutic citizenship (somewhat narrowly) to analyse how ‘rights and responsibilities’ to nutritional support and various social services for people with HIV/AIDS are debated and worked out in the three Catholic organisations.

However, I also move the analyses in a broader direction by considering those who are not in a position to easily become ‘therapeutic citizens’, such as those who struggle merely to guarantee existence and must work hard to keep “philanthropic, nongovernmental, and medical support in place to guarantee the effectiveness of the therapies” (Biehl 2007: 97). I will also consider other forms of sociality beyond bio-sociality in both the ‘treatment, care and support’ programmes and in the lives of people with HIV/AIDS in Ugandan settings (cf. Meinert et al. 2009). All these points are further elaborated in the final section of this chapter.

Governmentality and neo-liberal rationalities

Authors like Nguyen and Biehl often make references to Foucault’s analysis of ‘governmentality’, placing particular emphasis on neo-liberal governmentality. By using these terms, they generally point to contacts between the exercise of power and practices of the self (cf. Nguyen 2005). With the emphasis on neo-liberal rationalities of government, they point specifically to how states and international donors, in the realm of AIDS treatment, seek to govern through ‘civil society’ (e.g. Biehl 2007:11) and responsibilised individuals (e.g. Kalofonos 2008).

Governmentality studies are sometimes criticised for producing an image of a ‘perfect synthesis’ of neo-liberalism or a well-oiled machine of disciplinary and bio-power (Mosse 2005: 14), thus glossing over great diversity in and within different contexts (Gould 2005: 65), and leaving out the possibility of disconnect or contradiction within and between different rationalities of government. Because of such criticism, and the sometimes problematic ways that the governmentality concept is used in both the study of international development and health, it is necessary to clarify how I understand and employ ‘governmentality’ as an analytical lens, as well as its limitations.

Government: the conduct of conduct

Central to the question of ‘governmentality’ is the concept of government. Discussing the exercise of power as basically “less a confrontation between two adversaries or their mutual engagement than a question of ”government”” (Foucault 2002d: 341), Foucault shifts away from the focus on discipline and domination with which he is often associated. Government conceptualises the exercise of power as a matter of both

recognising and seeking to *shape* the freedom of those governed¹³. A relationship of power, Foucault writes, is defined as “a mode of action that does not act directly and immediately on others. Instead, it acts upon their actions: an action upon an action” (Ibid: 340). In acting upon actions, the other person’s ability to act is not only assumed, but also required. Exercising power is thus “always a way of acting upon one or more acting subjects by virtue of their acting or being capable of action” (Ibid: 341). In sum, power does not take away our freedom. Rather, power relations presuppose subjects that have some degree of freedom to act, which can be structured; “power relations are possible only insofar as the subjects are free” (Foucault 1997: 292).

Employing the word ‘conduct’ in several ways, Foucault further clarifies this perspective. According to Foucault, conduct can mean to lead someone, it is also a reflexive verb referring to how one conducts oneself, and a noun referring to a person’s conduct in a given situation (Foucault 2002d: 341; Dean 2004: 10). Exercising power is about conducting the conduct of others, as well as conducting *how* others conduct themselves: “the exercise of power is a “conducts of conducts” and a management of possibilities” (Foucault 2002d: 341). Exercising power is thus, Foucault argues, a question of ‘government’ in the very broad sense characteristic of 16th century Europe. At that time, ‘government’ referred not only to political structures, the management of states, or the legitimately constituted forms of political or economic power, it also referred to how the conduct of individuals or groups could be directed – to ways of acting upon others’ possible actions. “To govern, in this sense, is to structure the possible field of actions of others” (Ibid: 341). The notion of government as ‘the conduct of conduct’ is a central analytical concept in this dissertation, emphasising the ambiguous and open-ended character of ‘government’ I wish to explore in the three Catholic organisations.

Governmentality and liberal rationalities of government

The term ‘governmentality’ allowed Foucault to study government as the conduct of conduct along two lines of inquiry (Bröckling et al. 2011: 2). First, with the term governmentality, Foucault aimed to study “the contact between the technologies of domination of others and those of the self” (Foucault 1988: 19). Because if government is to govern how others conduct themselves, forms of political government have to resort to “processes by which the individual act upon himself” (Foucault 1993: 203). Secondly, with governmentality Foucault also pointed to the way in which the problematic of *how to govern* was increasingly *rationalised* – that is worked out according to calculations of force, relations, strength and

¹³ Thanks to Kaspar Villadsen and Kathrine Hoffmann Pii for offering this precision.

wealth (Foucault 2009: 311). This analytical interest is connected to the relationship between techniques of power and forms of knowledge, which also informed his previous analysis of for example sexuality and prison practice (Foucault 1978; 1977). Combining these two perspectives, Foucault analyses the gradual ‘governmentalization’ of the modern Western state (Foucault 2007: 109), as a matter of a “tricky combination in the same political structures of individualization techniques and of totalization procedures” (Foucault 2002d: 332).

In the Birth of Biopolitics lectures (Foucault 2009), Foucault analysed different liberal and neo-liberal rationalities of government. These analyses shed light on the different ways that the relationship between freedom and power; between techniques of domination and of the self, was rationalised and debated between the 17th and 20th centuries.

In the final lecture, Foucault argued that the liberal art of government is characterised by efforts to work out the problem of how to exercise government in a space of sovereignty when the space to be governed is inhabited by economic subjects¹⁴ (Foucault 2009: 291-4). The answer to this problem, Foucault argues, is the notion of ‘civil society’. Civil society is therefore not a philosophical idea, but a concept of governmental technology (Ibid: 295-6): “civil society makes it possible to designate and show an internal and complex relationship between the social bond and relationships of authority in the form of government” (Ibid. 308). The liberal art of government is a government that aims to manage civil society, while respecting its autonomy, and its spontaneous ways of operating and regulating itself (Ibid. 296-312). Moreover, liberalism as a form of critical reflection on governmental practice is characterised by a suspicion that one always governs too much. Governmentality should not only question the best or least costly means for achieving its effects, it should question “Why, after all, is it necessary to govern?”, and it is with reference to ‘civil society’ that this question is to be worked out (Ibid. 319).

Foucault also discussed different neo-liberal rationalities emerging in the 20th century, focusing on the Chicago School of Economics and the German *ordo-liberals*. The lectures illustrate significant differences between the problematisations of government and the solutions proposed by these neo-liberal debates. Most recent analyses of neo-liberalism take departure in the principles envisioned by the Chicago School – that the rationality of the market is to be extended to domains, which are not exclusively or primarily economic (cf. Foucault 2009: 215-290). For

¹⁴ Foucault refers here to the central notion in economic thought since the 18th century of a market regulated entirely by the spontaneous self-interest of rationally behaving individuals – *homo æconomicus* (Foucault 2009: 291-2).

example, Rose & Miller (1992) analyses the ‘neo-liberal turn’ in Europe and the US from late 1970s onwards. This neo-liberal turn is characterised by a re-centering of the problematic of governing too much; the welfare state is problematised for producing a culture of dependency, for producing an expectation that “government will do what in reality only individuals can” (1992: 198) The individual’s capacity to provide for him or herself is thus to be reconstituted, and “(t)hose aspects of government that welfare construed as political responsibilities are, as far as possible, to be transformed into commodified forms and regulated according to market principles” (Ibid.).

In the realm of development assistance, market regulation and privatization became important components of the structural adjustment programmes championed by IMF and the World Bank from the 1980s. Within the health sector, for example, structural adjustment programmes required that African governments introduce cost-recovery schemes, such as user fees (O’Manique 2004). But more broadly, there was and is also a general concern that development assistance itself, like the welfare state, produces a culture of dependency.

Development through and development of ‘civil society’ in Africa

The relevance of analysing liberal and neo-liberal rationalities of government in this dissertation is that such analyses can help bring to light central ways that development assistance, in recent decades, has been problematised and new governmental solutions have been proposed. These are problematisations and solutions related to technologies of government that work through the creation of responsabilized citizen-subjects (cf. Ferguson 2010: 172).

Starting from the early 1990s, development assistance, especially to African countries, has largely focused on achieving development through establishing and nurturing ‘civil society’. The notion of civil society, and its presumed institutional form (‘non-governmental organisations’) has, since the 1990s, become popular among development agencies and development critics alike (Fisher 1997: 443-6).

Broadly speaking, the development of and through ‘civil society’ in African countries was meant to achieve two interrelated goals. First, in the intersection of a widespread disappointment with African states as vehicles of development and the neo-liberal turn, ‘civil society’ organisations promised to be more reliable implementing partners of development assistance (Ferguson 2006:102-3; O’Manique 2004: 62). Second, as part of a ‘partnership’ with the state and foreign donors, civil society organisations were also seen as key to providing local accountability for the proper use of

donated resources (Hearn 2002: 50), and more broadly as holding governments accountable to its citizens (Igoe & Kelsall 2005: 13).

Related to neo-liberal rationalities of government, 'civil society' organisations were thought to be crucial partners in practising 'sustainable development' (cf. Danida 2000). The idea of sustainable development started to take shape around the late 1980s, based on concerns that development assistance had produced a culture of dependency. Development projects in many African countries had not effected the lasting social change envisioned. In response, sustainable development marked the search for means of instigating lasting social change that would continue after the donor funding ended. Therefore, instead of being passive recipients of charity, communities and individuals must become self-activating and responsible for their own development. The discourse on sustainable development was marked by terms such as 'empowerment', 'participation' and 'capacity building' (Fisher 1997; Kelsall & Mercer 2003; see e.g. World Bank 1994; Mansuri & Rao 2004). In line with rationalities of 'sustainable development', channelling development aid to civil society organisations was envisioned as a way to harness and foster the capacity for self-government in 'the communities' these organisations were assumed to represent (Kelsall & Mercer 2003; Nguyen 2005: 129). The 'sustainability doctrine' continues to constitute a central rationality in development assistance today, which also structures the types of activities that can be funded by development aid¹⁵.

Channelling large amounts of aid from both Northern governments and NGOs to 'civil society' in African countries have a number of paradoxical effects. Firstly, these funding flows help constitute a veritable market for 'non-governmental organisations', 'community-based organisations', and recently 'faith-based organisations', so that NGOs and CBOs are often established where none existed before (Igoe & Kelsall 2005: 6-8; Swidler & Watkins 2009). Secondly, as a result of their growth and strengthening in light of the 'sustainability doctrine,' NGOs provide a large share of basic social services previously under the purview of the state (Ferguson 2006: 38-9). Many of these NGOs are as much expressive of international organising as of local 'grass-roots' (Bornstein 2003; Barr et al. 2005). As mentioned in the introduction, in Uganda this development was particularly relevant in the AIDS field.

Analysing neo-liberal development rationalities

As 'civil society' or 'community-based' organisations the three Catholic organisations I study operate in this context of neo-liberal development rationalities. For example, it is according to such rationalities that an

¹⁵ For a recent example see Swidler & Watkins 2009 on AIDS-NGOs in Malawi.

organisation like KCCC has been able to access a plethora of international funding, which has helped the organisation to grow from a Catholic lay initiative to a comprehensive ‘community development’ NGO. But beyond that, it is the question of the kind of subjectivities, which ‘sustainable development’ is meant to nurture that has my interest. I will analyse the ways in which the neo-liberal question of how to overcome passive aid dependency by encouraging responsible, self-activating individuals and communities, is debated and negotiated in the three Catholic organisations.

This kind of approach can run the risk of constituting neo-liberal rationalities of development as mysterious, agent-less forces. As some anthropologists point out, without a precise analysis of the politics and negotiations at the different levels of the aid relationship, such analyses may produce an image of a ‘well-oiled’ machine of neo-liberalism (Mosse 2005: 14; Gould 2005: 65). My analyses may suffer to some extent from this weakness, since I have primarily studied how neo-liberal rationalities manifest themselves in the three Catholic organisations, without exploring in great details the precise negotiations among and between different donors and actors within the Uganda AIDS policy space. However, the exploration of debates and negotiations *within* the local Catholic organisations illustrate how these rationalities may be taken up in divergent ways and resisted within specific ‘implementing’ organisations.

Technologies of the self

As illustrated above, neo-liberal governmentality constitutes a problematic of how to govern individuals’ self-conduct in ways that foster self-reliance. Questions of how the individual act upon himself is therefore a central governmental focus (cf. Foucault 1993).

In international AIDS programmes, questions of how to foster ‘self-help’ and ‘empowerment’ came on the agenda in the 1990s. The programmes aimed for a direct involvement of communities affected by AIDS and were inspired by approaches pioneered by affected communities in both the North and the South. The approach was named ‘Greater Involvement of People living with HIV/AIDS’ (GIPA) after the 1994 Paris summit on AIDS (Nguyen 2005: 127-8; see UNAIDS 1999). At the centre of the attempts to foster self-help and empowerment among people with HIV/AIDS was a range of what Nguyen calls *confessional technologies* (Nguyen 2010: 8). One method was training “Africans with HIV to “come out” with their stories of being diagnosed, and living, with HIV” (Nguyen 2005: 131). In effect, people living with HIV/AIDS were trained to talk about their innermost feelings in public (Nguyen 2009b: 360). Though such methods at first were met with silence, Nguyen argues that HIV-positive

individuals eventually took up the method of ‘testifying’ about their experiences in the late 1990s, to “fashion themselves” (2005: 131).

Having only themselves to rely on in order to achieve ‘the good life’ in the context of certain illness and death, these confessional technologies gave the opportunity for some people with HIV/AIDS to work out an “ethics about the care of the self and the relationship to others” through self-transformation (Nguyen 2009b: 373). Apart from ‘the testimony’, counselling has been another central confessional technology in AIDS interventions in Africa. From the onset of the international AIDS response in Africa, counselling was tied to testing for HIV, in ‘Voluntary Counselling and Testing’ programmes. Today, with the expansion of ARV treatment, counselling provided both by professionals and by HIV positive volunteers has become a central method in attempts to ensure treatment adherence.

The focus on confessional technologies can be linked to Foucault’s writing on practices and technologies of the self¹⁶. Studying technologies of the self, Foucault again reworked previous research questions, centering his attention on the relationship of *self with self*, rather than the relationship of self with games of truth or relations of power (Foucault 1992: 6). Technologies of the self,

“permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality” (Foucault 1988: 18).

In volume 2 and 3 of the History of Sexuality, Foucault studies technologies of the self in antiquity (Foucault 1990; 1992), as well as some considerations of technologies of the self in early Christianity (Foucault 1988). He argues that in early Christianity, *knowing oneself* became the principle of technologies of the self (Ibid. 21-22). The truth of the self, established through self-examination, became the basis for care of the self. In contrast, in antiquity, self-examination served the purpose of examining whether one’s actions and thoughts conformed to a philosophically defined truth of the good life (Taylor 2009: 13-4). In early Christianity, one technique of knowing oneself was permanent verbalization of one’s thoughts in the presence of another (Foucault 1988: 46-8). But the

¹⁶ With reference to technologies of the self, governmental technologies as well as medical technologies, technology in this dissertation refers to a practical art – a ‘way of doing things’. A technology consists of specific methods, tools, techniques, material objects, organisational methods, administrative procedures etc., as well as specific knowledge and skills required to put these techniques to proper use (cf. Jöhncke et. al. 2004: 388; Hacking 1996: 80).

manifestation of the truth of oneself was simultaneously a renunciation of that self, a form of self-destruction to bring one closer to God (Taylor 2009: 24). Foucault argues that from the 18th century to the present, “the techniques of verbalization were reinserted in a different context by the so-called human sciences in order to use them without renunciation of the self but to constitute, positively, a new self” (Foucault 1988: 49). According to Foucault, confessional technologies in the realm of, for example, psychology constitutes thus a break from the Christian confession’s original concern with renouncing oneself, locating instead the constitution of ‘self’ with the individual truth produced through verbalization.

With the term *pastoral power* Foucault discusses how such individualising tactics has become a way of integrating the individual’s self-government into the workings of the modern Western state. This phenomenon is part of ‘the tricky combination’, mentioned above, of individualization techniques and totalization procedures (Foucault 2002d: 332).

With pastoral power Foucault refers to the principle of the pastor ‘leading his flock’ as an exercise of power that aim to ensure individual salvation in the next world. The pastor uses techniques such as self-examination to produce ‘the truth’ about the individual (Foucault 2002d: 333), and according to this truth, the pastor guides the individual towards salvation in the next world. But spreading and multiplying outside the ecclesiastical institution, the objective has changed from “salvation in the next world [to] ensuring it in this world” (Ibid: 334). Consequently, ‘salvation’ takes on meanings such as health, well-being, security and protection from accidents. At the same time as its objectives change, the ‘officials of pastoral power’ increase, now including officials in the state apparatus, public institutions, private ventures, welfare societies, benefactors, philanthropists and in families. The individualising tactic of pastoral power consequently comes to characterize a whole series of powers: those of the family, medicine, psychiatry, education, and employers (Ibid: 334-5).

I will use these perspectives on technologies of self and the way they are connected to technologies of power to analyse counselling and ‘Positive Living’ practices. This focus includes on the one hand attention to how practices of government can be influenced and challenged by practices of the self. And on the other hand, how government also entails attempts to harness and foster particular practices of the self in order to promote certain forms of self-government (e.g. the self-activating development subject) or serve bio-political ambitions (e.g. prolong the lives of people with HIV/AIDS).

Ethical subject formation

The above examples of the confession and pastoral power point to the general tendency in modern Western society for governmental practices to appropriate and re-articulate the historical functions of religion (Burchardt 2009: 349-50). But currently, with religious organisations' involvement in HIV/AIDS intervention in African settings, religious organisations in a sense re-appropriate these individualising tactics and technologies of the self. Burchardt argues that when in the context of faith-based HIV counselling, religion increasingly concerns itself with health:

“It thereby re-claims and re-appropriates the ‘subjects of counselling’ and refigures the ‘objects of salvation’. The rhetoric, the instruments, even partially the objective of religious health counselling itself are now informed by psychological discourses of mental well-being” (Burchardt 2009: 350).

The counselling practices in the three Catholic organisations I studied are informed by psychological discourses in similar ways. Based on the South African context, Burchardt argues that the specificities of faith-based approaches to HIV counselling “lie in a peculiar mode of incorporating educative, medical, and psychological practices into the overall pastoral concern with shaping ethical selves” (Burchardt 2009: 350-1). Therefore, he argues that we can trace the emergence of post-secular forms of ethical subject formation (Ibid. 351).

From a slightly different perspective, Nguyen argues that ‘the testimonies’ of people living with HIV/AIDS in Côte-d’Ivoire and Burkina Faso were frequently couched in an evangelical idiom. The process of being diagnosed with HIV were often described as the beginning of a conversion-like process, “the first step on a road that lead to greater enlightenment and the adoption of a more responsible, moral life” (Nguyen 2009b: 372). It never became clear to Nguyen whether these evangelical idioms were historically connected to mission Christianity, and its emphasis on declaring conversion, or tied to the increasing popularity of Pentecostal Christianity (Ibid. 373). In the Ugandan context, Jørgensen has also studied the conversion-like character of Positive Living practices in the Catholic NGO, Reach Out Mbuya (Jørgensen 2006).

I will trace the connections between ethical subject formation and transformations towards *living positively* in the three Catholic organisations, but also importantly point to the sometimes uneasy relationship between these ethical concerns and the bio-political ambitions of ‘saving lives’ with antiretroviral treatment.

In the intersections between relations of power and practices of the self, I am thus concerned with the effects of governmental practices in the three Catholic organisations on the formation of subjects. I will consider, the

forms of person, self, and identity presupposed in these practices, and the kinds of transformation of subjects the practices seek (Dean 2004: 32) According to Dean, the point is not that governmental practices *determine* forms of subjectivity. Governmental practices,

“elicit, promote, facilitate and foster and attribute various capacities, qualities and statuses to particular agents. They are successful to the extent these agents come to experience themselves through such capacities (e.g. of rational decision-making), qualities (e.g. as having a sexuality) and statuses (e.g. as being an active citizen)” (Dean 2004: 32 - parenthesis in the original).

Vaughan’s (1991) study of colonial and missionary health practices in Africa warns against too quickly assuming effects of subject formation through medical rationalities. The attempts at ethical subject formation in the studied Catholic organisations should also not be automatically assumed to fundamentally alter the sense of self and the identity of people with HIV/AIDS. When studying subject formation in African settings, it may be particularly pertinent to empirically explore to what extent and how people identify with the kind of individualised forms of ethical subject-formation sketched above, insofar as notions of personhood may be more relationally defined (Becker & Geissler 2009: 19-21). I will attempt to explore these difficult questions with an emphasis first on the divergent ways counselling is practiced in the three Catholic organisations, and secondly by analysing the pragmatic side of realising the potentials of ARV treatment and ‘Positive Living’ in everyday lives.

Christianity, development and health

‘Religion and development’

Until the late 1990s, religion was in development circles generally viewed with suspicion – as an obstacle to development (Haynes 2007: 1; Clarke 2006: 835). In accordance with the modernization paradigm, development agencies tended to view religion as part of ‘tradition and culture’, which had to be left behind for the sake of modernization (Dilger 2009: 89). However, despite these suspicions, prior to the 1990s, many religious organisations were in fact receiving development funding (Haynes 2007), especially the mainline Christian churches (Clarke 2006: 836). Historically, missionaries in Africa played an important role in the provision of education and health services as part of the larger civilizing mission of colonialism. They can thus be viewed as predecessors of more recent practices of development aid (cf. Vaughan 1991; Hansen 1984).

However, it is only in recent years that ‘faith-based organisations’ have been conceived as crucial strategic partners in achieving ‘sustainable development’. As pointed out by Christiansen (2010), development

agencies tend to view religious organisations instrumentally, seeing them as particularly competent ‘civil society’ organisations through which to practice development. Religious organisations are often present in remote rural areas, boasting ‘trustworthy’ leaders and an altruistic member-based organisation often already involved in various voluntary activities. Thus, they are seen to be more capable than urban-based professional NGOs to reach remote communities ‘on the ground’. In this way, religious organisations are seen as promising partners in the search for sustainable development solutions (Christiansen 2010: 2, see e.g. Marshall & Saanen 2007; Haynes 2007: 3).

I will analyse how religious organisations’ involvement in AIDS treatment programmes characterised by such neo-liberal development rationalities might contribute to transform these organisations (cf. Maxwell 2006). As illustrated by Christiansen, the pastoral work of churches involved in development is often marked by unintended consequences (2010: 250-2). As outlined in the introduction, my focus is not on churches doing development, but on what can be termed ‘religious development organisations’, which are connected to the Catholic Church. Central to this dissertation is the question of how these organisations’ involvement in programmes to provide ARV treatment and care & support to people living with HIV/AIDS may reinforce, challenge or change Christian and particularly Catholic conceptions of ‘the good life’.

Conceptions of The Good Life

Despite the perceived opposition between religion and development, religious practice and development share common characteristics. Like other forms of government, development assistance is based on the utopian premise that government is not only desirable, but also possible, and that government can achieve its desired ends (cf. Dean 2004: 33; 12). A basic parallel between religion and development is the intention to enact specific conceptions of ‘the good life’ or ‘the good society’. Some scholars point to how the notion of transcendence similarly underpins development and most religions: “an implicit utopian realm in which the greater good is manifest” (Bornstein 2003: 2). More precisely, “The concept of development can be understood as transcendental in so far as its meaning extends beyond the limits of ordinary experience” (Beard 2007: 1). Green argues that development practice plays on “religiously derived imaginaries of transformation and ideas of salvation through altered subjectivities” (2010: 1).

In turn, as shown by e.g. Bornstein, in some religious NGOs in African countries, development and evangelization are seen as integral. Bornstein (2002; 2005) illustrates how notions of economic development and

Christian faith are interwoven in two protestant NGOs operating in Zimbabwe: World Vision and Christian Care. What is particularly interesting for this dissertation is her analysis of how NGO workers combined and merged ideals of religious and material progress. NGO workers expressed a holistic view of development, framing development as “a Christian act that involves the body and the spirit” (Bornstein 2002: 8). World Vision in particular promoted a ‘holistic’ approach to development that ‘bridges the gap’ between the material and the spiritual, and the rich and the poor. With holistic development you do not just take care of people’s material needs, you also aim to feed them spiritually: “As compared to missionaries of earlier eras who strove to save people from savagery, World Vision and Christian Care work to save people from poverty” (Ibid: 10). In reference to the discussion of pastoral power, we can thus say that for those NGOs, poverty reduction has become a new objective of ‘salvation’.

Though Bornstein’s analysis is based on Protestant organisations, and the emphasis on personal salvation as the road towards societal progress seem particularly Protestant; the central feature of using Christian notions to formulate a holistic approach to social change is remarkably similar to the practice of some Catholic organisations involved in HIV/AIDS interventions in Uganda.

Christian notions of suffering and healing

While the three Catholic organisations operate in a context of development rationalities, providing care and treatment to people with HIV/AIDS is also about suffering and healing. As Vaughan points out, The Christian Church has a long, varied history of healing, which have had a major influence on the development of ‘modern’ Western biomedicine (1991: 55-6).

From a Catholic social theory perspective, Catholic involvement with modern-day biomedicine can be rationalised as an imitation of Christ’s teachings: “Jesus gave the example of healing; anyone who would follow him must also be a healer. Therefore, the Church must manifest the healing mission of Christ” (Cochran 1999: 28). Importantly, following Jesus’ example not only requires healing the sick, but also identifying with the sick: “On the cross Jesus takes on the whole weight of physical and moral evil, especially suffering and death” (Ibid. 29). The notion of *wholeness* is therefore central for Catholic questions of suffering and healing; wholeness points to the final healing of a broken creation (Ibid. 28), and also to the ‘wholeness of the person’; “. . . it is in the unity of the body and soul that the person is the subject of his own moral acts” (John Paul II quoted in Pontifical Council for Justice and Peace 2004: 69).

According to Vaughan, the influence of Christian teaching on healing was especially relevant in the medical practices of Christian missionaries in Africa, which combined a “belief in the powers of biomedicine with a conviction that those ‘called’ to the medical professional were mere servants of the ‘Great Healer’ of souls” (Vaughan 1991: 56). Vaughan argues that the discourse of missionary medicine in Central and Eastern Africa did not reiterate the post-enlightenment body/soul division, but rather “constantly referred to their indivisibility” (Ibid. 73). In medical missionary accounts, diseases in Africa always stood for larger social ills. Medical missionaries attempted to achieve not merely physical transformations of the body, but also the creation of new subjectivities through evangelisation (Ibid. 73-4). For example, for the missionaries, high rates of infant mortality and malnutrition indicated the need to promote Christian notions of the family (Ibid. 68).

In Uganda, as in most of Africa, Christian missions provided most of the biomedical care for African communities in the early colonial period, and they were the ones setting up the first rural hospitals and clinics (Ibid. 56). When studying ‘local’ Catholic organisations and health facilities in Uganda involved with HIV/AIDS today, it thus does not make sense to make clear-cut distinctions between ‘Western’ and ‘African’ or between biomedicine and Christianity.

Within the emergent anthropological study of Christianity the importance of ethnographically studying specific variations of Christianity is emphasised (Cannell 2006; M. Green 2003: 1). Following this point, rather than invoking a predefined definition of Christianity, I am interested in exploring how counsellors and community workers in the three Catholic organisations frame and understand specific notions of healing as particularly Catholic, in relation to provision of care and treatment to people with HIV/AIDS.

Global assemblages and local translations

As outlined in the introduction, the key purpose of this dissertation is to approach the three Catholic organisations in Uganda as lenses through which to explore the implications of how ‘global AIDS treatment’ is currently practiced and debated. The crucial point I pursue here is not merely a view on the three Catholic organisations as specific practices of government representative of a global *regime of practices* (cf. Foucault 2002b: 225). Rather I focus on the interplay between global technologies and situated practices. Therefore I find the term *global assemblages*, developed by Collier & Ong (2005) useful.

Employing the term ‘global assemblages’, I can highlight how medical technologies (like ARV treatment) or confessional technologies (like counselling) are *global forms*, with capacities for “decontextualization and recontextualization, abstractability and movement, across diverse social and cultural situations and spheres of life” (Collier & Ong 2005: 11). However, the argument that Collier and Ong make is that such global forms interact with other elements, creating contingent, uneasy and unstable interrelationships. The product of these interactions can be termed a global assemblage: “An assemblage is the product of multiple determinations that are not reducible to a single logic. The temporality of an assemblage is emergent. It does not always involve new forms, but forms that are shifting, in formation or at stake” (Ibid: 12). The term global assemblage thus suggests inherent tension: global points to something broadly encompassing, seamless and mobile, and assemblage to the heterogeneous, contingent, unstable, partial and situated (Ibid.).

Understanding AIDS treatment as a global assemblage of governmental and medical technologies opens an analytical space for the situated ‘translations’ of these technologies. This also allows me to address the common critique that Foucault-inspired studies fail to move beyond the programmatic level of official discourse, policies and plans. Despite Foucault-inspired studies’ emphasis on the “relatively unpredictable consequences, effects and outcomes” of government (Dean 2004:11) or its unintended ‘side effects’ (Ferguson 1990: 20), the conclusions of these studies often seem given beforehand. More precisely, the critique is that these studies fail to consider the complexity of concrete practices, for example failing to study how medical programmes or development projects may be taken up in divergent ways, negotiated, contested or transformed by practitioners, ‘brokers’, patients and ‘target groups’ (Lupton 1997: 94-5; Mosse & Lewis 2006: 5).

My aim is to present an ethnographic study of concrete practices of AIDS treatment and care in Catholic organisations in Kampala and Arua dioceses, in order to highlight such complexity. Therefore, I will bring to the forefront how practitioners such as counsellors and community workers take up, transform, contest or negotiate central rationalities, technologies, and ways of forming subjects in divergent ways in everyday institutional practice.

Social technologies in everyday lives

In order to consider how people living with HIV/AIDS attempt to ‘translate’ the potentials of self-government techniques and ARV treatment in everyday life, it is necessary to supplement the Foucault-inspired analytics with a number of ethnographic viewpoints.

Jöhncke and colleagues' (2004) discussion of *social technologies* suggests a path for such an analysis. With the term 'social technologies', the authors generally refer to a Foucault-inspired approach to the study of government. However, by employing the word '*social*', they introduce a perspective on how these technologies are exercised and must be realised in social relations, as well as how such technologies target 'the social', in the form of relations between persons, entire societies, or populations (Jöhncke et al. 2004: 388-9). They propose that by analysing government programmes promising to solve particular social problems (e.g. to address the AIDS epidemic) as social technologies, it is possible to explore how the connections between techniques, moral perspectives and social actors are produced in specific contexts.

They propose that we ask: what part do social technologies play in forming bodies, lives, social relations and socialities? How do social technologies become a factor in people's everyday lives, if at all they do? The authors emphasise that even if some social technologies become dominant, and therefore difficult to ignore, they do not produce the same effects for everyone (Ibid: 394-5). More precisely, they outline three areas of inquiry: how social technologies have consequences for identity, how they open and closes certain possibilities for action, and how they engender new reflections. Here I only consider the two first, identities and possibilities for actions.

Identities and socialities

Regarding identity, Jöhncke and colleagues argue that not everyone who is the target of social technologies accepts to be constituted as a problematic subject (the example the author provides is of a 'drug addict'). People may resist, diverge from, critique and doubt the rationalities proposing how their problems should be solved. Other perspectives than those implied in 'the solution' of the social technology may seem more relevant to the very people those technologies aim to target (2004: 395-6). The authors argue that except when people completely resist belonging to the category of a problematic subject, most people attempt to make the solutions proposed by social technologies meaningful to their own lives, or at least try to live with these solutions in the context of their everyday lives (Ibid: 397).

In 'treatment, care and support' programmes for people living with HIV/AIDS in Uganda, challenges surrounding identity are first of all reflected by the considerable amount of time and energy programmes spend attempting to get people to become 'a client' – efforts that often end in failure. Some people refuse to be tested for HIV or to 'accept' their HIV positive diagnosis, and many choose not to disclose their HIV status publicly. I will therefore focus on the divergent ways people become

clients in treatment programmes, especially when an HIV positive identity may not be easily reconcilable with existing identities or life situations. For example, Blystad & Moland's (2009) study of HIV positive mothers in Ethiopia illustrates that in the situation of pregnancy and childbirth, being public about one's HIV status may be particularly difficult. Because of incongruities produced in 'Prevention of Mother to Children Transmission' (PMTCT) programmes between notions of maternal love and nurture on the one hand, and HIV, sexuality and death on the other hand, the women "resort to non-disclosure and social caution rather than disclosure and social exposure, which is demanded when the HIV positive status is to be drawn upon in quests for respect and resources" (Blystad & Moland 2009: 116).

The question of HIV positive identity also links to the discussion of 'biosociality'. 'Therapeutic citizenship' emphasises how people may organise themselves and make claims on the basis of HIV positivity. Though HIV positivity is a central requirement for accessing ARV treatment and different forms of social support in Uganda today, Meinert et al. (2009)¹⁷ argue that patron-client socialities and family and friendship socialities remain the most central and enduring social networks for people living with HIV/AIDS. The social technology of ARV treatment programmes, they argue, become part of everyday interactions *within* these social networks, only in some instances leading to people feeling that they have become part of a kind of 'biosociality' or a therapeutic citizenship (Meinert et al. 2009: 206). In the uneven Ugandan social landscape and the unequal provision of ARV treatment, access to treatment is necessarily mediated through social relations. Their study therefore highlights "the intensely social character – the unequal but personalised relationships – of accessing ART and staying alive" (Ibid.).

Meinert and colleagues' attention to clientship highlights the process by which individuals become enrolled in ARV treatment programmes as 'clients', with the right to access certain services if they live up to and successfully navigate certain institutional norms and procedures. Therefore the "sociality of being a client involves respecting the programme being 'docile' and grateful" (Ibid: 205). The notion of 'clientship' thus grants attention to the hierarchical relations between the individual and the programme, in contrast to the bio-sociality and solidarity implied by the therapeutic citizen notion (Ibid.).

¹⁷ This study is part of larger collaborative research project between Danish and Ugandan researchers, conducted between 2003 and 2007 on 'the first generation' of Ugandans living with ARV treatment. Some other publications include Meinert, Whyte M., Whyte S. & Kyaddondo 2003; Mogensen 2010; Mogensen 2009; Whyte S., Whyte M. & Kyaddondo 2010; Whyte S., Whyte M., Meinert & Kyaddondo 2004.

More precisely, a key focus of the forthcoming analysis is what exactly being ‘a client’ (which is the general term used for people with HIV/AIDS in treatment programmes in Uganda) entails in the three Catholic organisations. I draw upon Meinert et al. (2009) to focus attention on how people relate to the potential of an HIV-positive identity and the relevance of different socialities, from the viewpoint of how people living with HIV/AIDS can and do engage with the treatment programmes as ‘clients’.

Possibilities for action

Another central contribution of Jöhncke and colleagues is highlighting how people try to unfold the technology’s potentials within the goals and challenges of their own lives (2004: 397). They argue that ethnographers should examine how certain social actors in specific situations appropriate rationalities and techniques and use them to realise the potentials and promises of the social technology (Ibid: 398). As outlined in the introduction, I aim to explore struggles and challenges underlying the potentials and promises of ARV treatment and ‘Positive Living’ for people living with HIV/AIDS. To examine such questions, I take inspiration from a pragmatic medical anthropology (Whyte 1997) and anthropological studies of medicines in developing countries (Whyte et al. 2002; Van der Geest & Whyte 1998).

Susan Whyte’s pragmatic approach to medical anthropology is developed out of her long-term studies of the Nyole in Eastern Uganda. She argues that when addressing misfortunes, the Nyole are “engaged in a search for security rather than a quest for certainty” (1997: 3). Her entry point is the fundamental uncertainty, precariousness and ambiguity of human existence (Ibid: 18-9). Responding to misfortune is therefore a matter not of finding security, but of engaging uncertainty in order to change it (Ibid: 13). In doing so, people use ideas from their social experiences. Whyte calls these ideas ‘idioms’, which are “guides to action that are in common currency in a community (shared, like a dialect), that convey meaning and are understood like a vocabulary, and that constitute a situation in a particular way, as Foucault meant that discourse does” (Ibid: 23, parenthesis in original). Whyte argues that idioms operate as starting-points for action, not as finalities (Ibid: 20). Responding to misfortune is an uncertain enterprise – there is no guarantee of success. People try out different approaches, perhaps fail and may try out other approaches. Trying out one particular ‘answer’ to the causes of misfortune may produce further uncertainty about how to deal with the affliction and about agents and social relations (Ibid: 21-2).

Whyte identifies two central idioms for addressing the uncertainty of misfortune among the Nyole. One is the explanatory idiom, which

identifies a personalistic agent as the cause of affliction, and therefore addresses misfortunes through emphasis on social relations, especially kinship relations. The second is the symptomatic idiom, which brings the power of substances (pharmaceuticals or African medicines) to bear on problems (Ibid: 23). In the 1990s, the advent of AIDS and information campaigns about AIDS contributed to “the emergence of a new idiom of action in relation to the uncertainty of misfortune: an idiom of individual responsibility for avoiding affliction” (Ibid: 223). The idiom of individual responsibility to avoid affliction also underlines other current forms of health promotion, such as immunization programmes.

From this perspective, both HIV/AIDS prevention methods and the idea of ‘living positively’ with HIV/AIDS constitute idioms of individual responsibility for avoiding affliction. However, with the greater availability of ARV treatment across Uganda, there is now also a possibility of responding to AIDS with the use of medical substances, not only with the ARV treatment itself, but also with the prophylactic treatment¹⁸, which are provided in treatment programmes.

As medicinal substances, ARV medicines are assumed to have transformative powers. But like other medicinal substances, they hold the potential to be both harmful and beneficial (cf. Whyte et al. 2002: 5-6). I will explore how notions of the simultaneously harmful and beneficial potential of ARV medicines are produced in the Catholic organisations. I also point to how ARV medicine is provided and experienced as something exceptional in Uganda (Whyte 2008). In Uganda, medical substances – whether pharmaceutical or herbal remedies – are most often targeted at specific symptoms. Health workers, drug shop owners and the patients themselves often target pharmaceuticals towards specific symptoms rather than pathological processes (see e.g. Whyte 1997: 212-3). Secondly, pharmaceuticals can often be purchased without prescriptions in small drug shops to the pocket and convenience of the customer (Whyte 1998; Walman 1996). In this respect ARV medicines are different than other pharmaceuticals, because they have to be taken for the rest of one’s life, even after symptoms cease. And except for the few people who can afford to buy them in private clinics, ARV medicines can only be accessed if one becomes ‘a client’ in a treatment programme.

Highlighting the pragmatic view on misfortune allows me to emphasise the practicalities and pragmatics people face when trying to realise the potentials and promises of ARV technology in the final chapter. I wish specifically to stress how the practicalities of taking ARV medicine may produce new questions and thereby further uncertainties about sexual

¹⁸ As a prophylactic treatment, the antibiotic medicine co-trimoxazole is provided.

relations, kinship relations or livelihoods, and how in the Ugandan context these practicalities are significantly structured by ‘the intensely social character’ outlined by Meinert et al. (2009). The attention to social agents and agency in Susan Whyte’s pragmatic approach seems perhaps incompatible with a Foucault-inspired framework. Foucault’s conceptualisation of government as the conduct of conduct, and his discussions of practices of the self do emphasise acting subjects to a large degree, but I view pragmatic medical anthropology as a supplementary approach. I add this approach in the final chapter, to underscore how the governmental practices are also just ‘starting points, not finalities’ for people living with HIV/AIDS.

It must be clarified here that my primary concern is how people with HIV/AIDS engage with the programmes as ‘clients’, and therefore the pragmatic medical anthropology optic is not used as a broadly encompassing approach to analyse all the different approaches to AIDS-related misfortunes that may exist in Kampala and Arua. I only emphasise one option in a broader therapeutic economy. Questions of how AIDS treatment is experienced and possibly changed vis-à-vis explanatory idioms in the local settings are left out of the analysis. This analytical interest is also reflected by the kind of ethnographic studies I have conducted in Uganda, which are outlined in the following chapter.

Conclusion: analytical framework

The analytical framework outlined in this chapter provides an approach to studying the three Catholic organisations in Kampala and Arua as *practices of government*. With practices of government I understand specific institutional assemblages of governmental rationalities, forms of knowledge, technologies and ways of forming subjects (cf. Dean 2004: 30-32). In the analysis, I place emphasis on the negotiations within the three Catholic organisations around bio-political ambitions, neo-liberal development rationalities and Catholic notions of healing.

With the concept bio-politics I highlight the global political ambitions to ‘save lives with ARV treatment’, in which the Catholic organisations operate. But I also direct attention to how such bio-political ambitions are negotiated or at odds with concerns of ‘governmentality’.

The governmentality concept directs attention to the interrelations between technologies of power and technologies of the self. This perspective is first of all used to explore the tensions and negotiations between psychological techniques of self-transformation, ethical subject formation and bio-political ambitions. Secondly, I consider especially the ways that neo-liberal development rationalities propose to overcome

passive aid dependency, by encouraging self-reliant individuals and communities, and how such rationalities are debated and negotiated in the three Catholic organisations.

With regards to Catholic notions of healing, I explore how counsellors and community workers frame and understand specific notions of healing as particularly Catholic, when debating how to provide care and treatment to people with HIV/AIDS. This will include considering how the involvement in ARV treatment programmes have reinforced, challenged or changed such conceptions.

For the final chapter, I employ ethnographic perspectives on identities, socialities and possibilities for action, to analyse how people living with HIV/AIDS attempt to realise the potentials of these self-government techniques and the ARV medicine in their daily lives. With these perspectives, I analyse the uneven ways people accept to become 'clients' in treatment programmes. I also explore the relevance of different socialities for the practical attempts to realise the life-prolonging potentials of ARV medicine.

3. Fieldwork

Introduction

This dissertation is based on a total of ten months' fieldwork in Uganda. From March to June 2008, I conducted preliminary studies in Kampala and Arua. From December 2008 to May 2009, I focused on the study of counselling and home visits in the three Catholic organisations. In July 2010, I returned for a short follow-up visit to the organisations.

By definition, ethnographic research constitutes a specific and partial perspective on the world. This perspective is structured by the ways in which the ethnographer has gained access into and delineated the social setting he or she studies (see e.g. Hastrup 2003; Davies 2003). Therefore, the purpose of this chapter is to explicate how my particular perspective was produced by accounting for the 'path' I followed during the fieldwork, in terms of methodological choices and the ways in which I negotiated access into 'the field' (cf. Sanjek 1990).

The point of dividing the fieldwork into first a shorter stay and then a longer stay was to use the first stay as an exploratory way of defining my analytical focus. In the first part of this chapter, I therefore discuss how my initial experiences in 2008 in various Catholic AIDS projects and national coordinating bodies led me towards the analytical focus outlined in the two previous chapters. When I returned to Uganda in December 2008, I pursued a more fixed plan, focusing on participant observations of counselling and home visits, and interviews with counsellors, community workers and clients in the three Catholic organisations. In the second part of the chapter, I discuss how I chose to use these methods in consideration of both practical and ethical challenges. I consider the ways that I did and could negotiate access into the three organisations and to counselling and home visits specifically. Finally, I conclude with discussing the ethical challenges of my fieldwork.

March-June 2008: Mapping and exploring the field

I began the fieldwork in Uganda with the objective of studying AIDS projects related to the Catholic Church, and with an intention to combine my long-held interest in Foucault-inspired analysis with ethnographic

studies¹⁹. I came with experiences from the Catholic NGO Reach Out Mbuya in Kampala²⁰. These experiences had given me a sense of the contradictions between HIV prevention and care for people with HIV/AIDS in Catholic organisations, as well as insights into the way Christianity and development can be combined in a framing of holistic HIV/AIDS care.

But besides this, I initially approached the fieldwork with an exploratory stance. I wanted to choose which specific projects to focus on and define the analytical focus through a greater appreciation of what was at stake in the field of Catholic-related AIDS projects²¹. After choosing two or three organisations to focus on, I wanted to conduct preliminary studies in these organisations to further thematically define my analytical focus.

Getting an overview

To pursue this exploratory plan, I began the fieldwork trying to gain an overview of different types of Catholic-related AIDS projects in Uganda. I first participated in meetings, collected documents and interviewed officials in the national coordinating bodies, the HIV/AIDS Focal Point Office and Uganda Catholic Medical Bureau, both part of the Uganda Catholic Secretariat (the administrative section of Uganda Episcopal Conference). I also interviewed officials from intermediate funding organisations that channel PEPFAR funding to various Catholic organisations.

One of the decisive events during this time was my participation in a meeting with DFPs from different dioceses. DFP stands for the Diocesan HIV/AIDS Focal Person, who is appointed in each Catholic diocese to coordinate HIV/AIDS activities. The meeting left me with a wealth of insights into the administrative and financial challenges the DFPs in more remote dioceses of Uganda experienced when coordinating HIV/AIDS activities. Compared to the quite professional and well-funded Catholic NGOs I was familiar with in Kampala, there seemed to be different

¹⁹ I have a background in International Development Studies and Public Administration. During my bachelor and master's studies I conducted a number of Foucault-inspired studies of development assistance, social policy in Denmark, as well as new management approaches.

²⁰ From January to June 2006, I completed an internship in Reach Out's microfinance department, and from July to August 2006 I conducted research for my master's thesis in Reach Out's HIV prevention programme targeting men, along with another prevention project targeting men (see Rasmussen 2008).

²¹ I had decided not to focus on Reach Out again, because several Danish-based researcher had already conducted research there. I therefore found that focusing on other organisations could contribute with new insights to the study of Catholic AIDS projects.

problems in areas less centrally placed in Uganda's development economy (cf. Jones 2009).

The meeting thus made me reflect on the possible different trajectories, dilemmas and challenges of Catholic AIDS projects in Kampala versus in 'up-country' dioceses. To explore the possibilities of choosing organisations in two such different settings I went to visit various Catholic organisations first in Kampala, and then in Arua (in the northwest) and Fort Portal (in the west). When visiting these organisations, I came with a guide for the kind of information I wanted to collect for each organisation (see appendix 3).

Mapping organisations and choosing cases

In Kampala, I visited three different organisations (see appendix 2). It was the kind of community-based organisation turned into NGO, which is a particular Kampala phenomenon that I found most interesting. I assessed that this kind of organisation could add to the experiences I had gained in Reach Out in terms of the use of 'holistic care' rationalities in AIDS interventions. I therefore chose to focus on Kamwokya Christian Caring Community, which seemed to have an even wider approach to 'holistic care' than Reach Out and placed an even greater emphasis on its rooting in Catholic lay organising.

Outside Kampala, I chose to visit Arua (for three days) and Fort Portal (for two days). The choice of these two locations was based on practical considerations around time and resources, my discussions with AIDS Focal point staff, and an intention to find a less researched area of Uganda. Apart from the fact that most research in Uganda is concentrated in Kampala, research on AIDS in Uganda has historically focused on the South-Western regions, where AIDS was first discovered, and in recent years on the post-conflict situation in Northern Uganda as well. Among Danish-based researchers, there are many who have conducted research on health issues in the South-Eastern parts of Uganda²². I therefore saw the West and the North-West as an opportunity to explore less researched areas of Uganda.

My final decision to focus on Arua was partly structured by the distinctive marginal position Arua seems to have in the Ugandan imagination. When I returned from my first trip to Arua, people in Kampala were a bit shocked that I had been there. They said things like 'isn't Arua a dangerous place?' or 'aren't these people very violent?' This figure of a distant, marginal place I found interesting for the purpose of exploring a setting less centrally placed in the Ugandan development economy. At the same time, the Arua

²² In connection with a research collaboration between Danish universities and Makerere University called Tororo Community Health.

DFP had from the first time I met him at the DFP meeting, been extremely interested in my research. For my first visit he had organised a comprehensive tour of the diocese's HIV/AIDS activities. The Catholic Church seemed to have quite a visible presence in Arua and the many different HIV/AIDS activities coordinated by the diocese meant that there was a wealth of different opportunities for me to develop a more narrow focus around.

Outcome of preliminary studies of KCCC and Arua Diocese

After the mapping process, I began preliminary studies of KCCC and Arua Diocese as a method of developing a more narrow analytical focus. The preliminary studies were thus conducted in different types of organisations, but this fact reflects a fundamental difference between the Kampala and the Arua setting; the sheer amount of programmes that one community-based NGO, KCCC, has compared to those that the whole of Arua Diocese coordinates.

In order to gain a broad overview of the interventions undertaken by respectively KCCC and those coordinated by Arua Diocese's AIDS Focal Point, I spent one month in each setting, conducting qualitative interviews with programme managers and participant observations of a broad section of their activities. I focused on capturing both HIV prevention and 'treatment, care and support' interventions (see appendix 2 for an overview).

Throughout these preliminary studies, the scale-up of ARV treatment was hard to evade. In the light of my interest in examining different types of Catholic AIDS projects, and my experiences with holistic care approaches in Reach Out, the different opportunities and dilemmas ARV treatment brought, sparked my interest. It was clear that the scale-up of ARV treatment provision was raising new important questions for Catholic organisations as well as people living with HIV/AIDS that seemed fundamentally different than the kind of questions raised by HIV prevention.

Therefore, I decided to focus on the scale-up of ARV treatment in the broader context of 'treatment, care and support'. For KCCC, this meant that I chose to focus on one aspect of their wide-ranging services. For Arua Diocese, it meant that I had to choose one or two organisations that were suitable for this focus. The AIDS clinic in Maracha Hospital and the home-based programme coordinated by Ediofe Health Centre, I found the most appropriate choices because they were essentially the only ones of the diocese's activities involved in either providing treatment or care and support to people with HIV/AIDS. I chose to focus on both of them, first because I was concerned with having enough width in terms of activities

compared to KCCC, and secondly because I found that the two organisations presented different entry points to the discussions of ‘treatment, care and support’. The AIDS clinic in Maracha Hospital illustrates the dilemmas of providing ARV treatment in a rural hospital under great resource constraints, while Ediofe’s HBC programme reflects a quite unique organisation of home visits, which has benefited from the connections of a European missionary and local Catholic church networks.

In sum, with the three Catholic organisations I have chosen to focus on, I have been able to produce a comparative perspective on the provision of ‘treatment, care and support’ to people living with HIV/AIDS in different parts of Uganda and in different types of Catholic organisations.

Fieldwork December 2008 to May 2009

For the main fieldwork from December 2008 to May 2009, I decided to focus on counselling and home visiting practices in the three Catholic organisations. This focus is a reflection of the theoretical interests outlined in the previous chapter. Because counselling and home visits are sites of central social negotiations around how to live with HIV/AIDS, I chose to use them as key sites to explore how the Catholic organisations attempt to promote certain kinds of self-government among people with HIV/AIDS, as well as how people with HIV/AIDS engage with treatment programmes as ‘clients’.

In order to examine counselling and home visiting practices, I chose a combination of participant observation and interviews. With this combination, the purpose was to explore on the one hand the governmental rationalities according to which social technologies like counselling and home visiting are employed. And on the other hand to explore their practical implementation in the wider social settings in which these technologies are placed, as a method to foreground the divergent ways counsellors, community workers and people with HIV/AIDS take up, transform and negotiate such technologies.

I chose to divide the six months fieldwork with two and a half months in Kampala and three and a half months in Arua. I was anticipating that because counselling and home visits take place more frequently in KCCC than in the two organisations in Arua, it would be beneficial to have more time in Arua. Spending more time in Arua was also an attempt to strike a geographical balance, since I had already spent much in Kampala, during the initial research with national coordinating bodies.

Participant/observation

The main component of my fieldwork was participant observations focused on counselling and home visiting. As a reflection of my Foucault-inspired interest in counselling and home visiting as *technologies of government/the self*, I had an interest in *observing* these technologies as they were practically implemented and translated by counsellors and community workers in interaction with the clients. However, I also wanted to situate these practices with ethnographically oriented *participation* in the organisations – understood as seeking an immersion in a defined social setting to understand what people in these settings experience as meaningful and important (Emerson et al. 2005: 2; Hastrup 2003: 10)²³. As I will discuss below, these two methodological interests at times pulled me in different directions.

Kamwokya Christian Caring Community (Kampala)

In KCCC, I was focused on the one hand on observing as many counselling sessions and home visits as possible and taking notes about what was going on. From December 2008 to February 2009, I spent three days a week following the community health workers on home visits and two days a week with the counselling department observing counselling sessions. As an ethnographic practice, this can be characterised as participating “in ways that directly and immediately involve inscription. Here the fieldworker is concerned with “getting into place” to observe interesting, significant events in order to produce a detailed written record of them” (Emerson et al. 1995:18). This kind of attention affected the kind of relationships I was able to establish with counsellors, community workers and clients, since I became primarily a researcher who was interested in documenting (certain) things.

On the other hand, I also aimed to participate in the everyday life of KCCC to gain a broader perspective on the social and moral stakes in the organisation. To do so, I spent every weekday at KCCC during the office hours and participated in activities such as the daily morning prayers, lunch and tea breaks, as well as in general and departmental meetings. I also interacted with counsellors, community workers (and other staff) as I was waiting to observe counselling sessions and go on home visits. At the same time, I wanted to capture how clients interact with the programmes as

²³ It should be noted that there is no general agreement about the term participant observation in anthropology or in the social sciences at large. The principles mentioned here are oriented most towards the phenomenological approach to participant observation, which stresses the aspect of participating, and views the method as a way of producing insights about others by trying to live and act as they do (cf. Gammeltoft 2003: 279).

'clients' viewed in the broader context of their everyday lives. This worked best in connection with home visits where there were greater opportunities to get a sense of how the clients' everyday lives and agendas were negotiated with living on ARV treatment.

Maracha Hospital AIDS clinic (Arua)

In the AIDS clinic in Maracha Hospital, I focused my attention on observing the counselling/consultation sessions for clients conducted by the clinic coordinator in her capacity as nursing assistant/counsellor. From March to May 2009, I observed these sessions on the clinic days Tuesdays and Fridays. I basically spent the entire time in her consultation room as clients came and went. Home visits did not take place in the clinic as frequently as I had anticipated, but I managed to organise three days of home visiting with the clinic coordinator. In the beginning of my time there, I also participated in two testing outreaches.

In the AIDS clinic in Maracha my attention was, compared to in KCCC, even more directed towards 'getting into place' to observe the counselling sessions, and I did not otherwise participate much in the daily life of the hospital. I interacted with all the counsellors while I was in the clinic, but when the clinic days were over around lunch-time (1-2 pm.), I usually drove back to Arua. My practices in this clinic gave me few opportunities for more informal interactions with clients, but on the few home visits, I managed to gain a broader perspective of the contexts in which clients were negotiating living with HIV/AIDS.

The home-based care programme coordinated by Ediofe Health Centre (Arua)

Because of the way home visits are organised in the Ediofe programme, I decided to rely on the coordinator to arrange for home visits I could participate in. In contrast to KCCC, these community workers do not take off every morning from a central location; but live in their respective villages all over Ayivu county. They go on home visits within the sub-county where they live, not as a daily job or according to any overall plan. As a consequence of this arrangement I was dependent on the coordinator to establish contact with the community workers. We agreed on two days a week where I could participate in home visits (Wednesdays and Sundays). He then contacted the community workers, enquired if they were willing to participate, which date, and asked them to select one or two clients it would be suitable for us to visit. Many of these 'appointments' were cancelled in the very last moment (there were funerals, misunderstandings about dates, clients who had been admitted or died etc.). These cancellations meant that from March to May 2009, I only went on five home visits.

On the home visits, the coordinator came along, since I relied on him to locate the community worker or the client we would visit. This entire set-up meant that in most instances the home visits turned into semi-interviews of the client and the community worker, mediated by the coordinator. As a consequence, I did not manage to explore the work of, interact with neither the community workers nor their clients to the extent I would have liked to²⁴. In contrast to the kind of home visits I participated in KCCC and with Maracha's clinic coordinator, these home visits gave limited insights into the kind of interactions that may take place between these community workers and clients. But what I did gain from these experience was an insight into the rather loose relationship between the health centre and the community workers, The last minute cancellations also indicated that perhaps not all of the community workers go on as many home visits as they would like to the health centre to believe. Additionally, I managed to conduct a few good interviews with some of the most 'active' community workers (see below).

Other activities in Arua

In Arua, I also conducted participant observations in a few other contexts. At Ediofe Health Centre, a post-test club, initiated by one of the community workers, meets once a week. To ensure more interaction with clients in the Arua setting, I participated in five of their meetings.

The clients visited by the Ediofe community workers are patients in the AIDS clinic in the government-run Arua Hospital. This clinic also function as a referral option for the AIDS clinic in Maracha, for second-line ARV treatment and CD4 counts. Because of these connections, I decided to also observe a few of the counselling sessions in this clinic.

Noting practices

As pointed out by Emerson et al. ethnographic field research not only involves participant observation, but also the process of turning the observed and learned into text, i.e. writing fieldnotes (1995: 1). During the above-mentioned observations of counselling sessions and home visits, I concentrated on writing as much of the dialogue and notes about the interactions taking place during counselling sessions and home visits as possible, mostly while they were going on²⁵. My attention was directed

²⁴ In retrospect, I think that it would probably have been a more fruitful approach to establish a closer relationship with one or two of the community workers and arrange the home visits with them independently.

²⁵ When I typed these notes at the end of the day or the week I usually included more details, as best as I could recollect. However after I moved to Arua, an unfortunate time lag in typing the notes developed, because for the 4 months I lived there in 2009, there was no electricity supply.

particularly towards capturing the kind of communication techniques used in counselling and during home visits.

Apart from these notes, I also kept a diary, which focused on reflections on my own position and relationships with various informants. I also noted from broader experiences in and outside the three Catholic organisations. These notes have primarily been used to present my methodological reflections in this chapter, but a few of these kinds of reflections are also included in the analysis.

In sum, a main aspect of my fieldwork consisted of *observing* counselling sessions and home visits as ‘significant events’ in order to produce a detailed written record of them. The strength of this component of my fieldwork lies in the detailed records I have of counselling and home visits interactions.

On the *participant* side of my practices, I will elaborate in the section below on negotiating access and positions.

Interviews and focus group discussions

Apart from participant observation, I also relied on conducting qualitative interviews of various kinds. I conducted semi-structured interviews with programme coordinators, counsellors, community workers, a few clients in all the three Catholic organisations, and focus group discussions in KCCC. Note that the below discussion of interviews refers to interviews conducted both in March-June 2008 and from December 2008 to May 2009.

Overview of central interviews

In KCCC, I interviewed all the coordinators of their different programmes in April 2008. In June 2008, I also decided to conduct two focus group discussions with various employees. In January-February 2009, I interviewed 8 counsellors, 9 community workers (with an emphasis on those who were also ‘clients’ themselves), and 5 clients.

In Maracha Hospital AIDS clinic, I interviewed 4 of their 6 counsellors (including the clinic coordinator who is a nursing assistant/counsellor), and conducted a group interview with the hospital’s medical director and community work coordinator in May 2009.

For the home-based care programme coordinated by Ediofe Health Centre, I interviewed the coordinator in May 2008. In May 2009, I interviewed 5 out of the 23 currently active community workers. This was fewer than I had hoped, but this was due to my difficulties with establishing contact with these community workers.

Types and focus of interviews

The interviews I conducted with programme coordinators, counsellors and community workers all followed the semi-structured format (cf. Kvale 1997). I worked with interview guides with a number of themes and suggestions for questions, but I added questions as I went along, following up interviewees' responses and adjusting to how the interview situation was evolving. The theoretically informed analytical themes I wanted to explore were rather abstract, but I attempted to translate them into concrete, descriptive questions as a method of opening up for detailed narratives (see appendix 4 for examples of the different interview guides).

The interviews with programme coordinators were mostly conducted during the initial fieldwork in March-June 2008 and as such primarily had the purpose of gaining an overview of the organisation's work. However, these interviews all proved central in elucidating the rationalities of different programmes and the kind of methods and techniques used to govern the conduct of people with HIV/AIDS. For KCCC, in particular, the interviews played an important role in illuminating the rationalities and negotiations around 'holistic care'.

In my interviews with counsellors and community workers, I asked to the rationalities and methods of their work in similar ways as I did in the interview with programme coordinators. But for them, I also emphasised discussing their experiences, successes and frustrations with doing counselling and home visits. This approach helped to explicate further how counsellors and community workers understood and attempted to put to use counselling and home visits as social technologies.

In the interviews with clients and with community workers who were also living with HIV/AIDS, I used the approach of asking to the decision to test for HIV as an opening question to the experience of living with HIV/AIDS. This approach was an attempt to play on a familiar way of talking about living with HIV/AIDS, namely 'the testimony', which is often used in post-test clubs or when people living with HIV/AIDS are enlisted in AIDS education programmes. Using a familiar approach, I assessed, could be a way to open up for a flowing conversation, but this approach also produced somewhat similar narratives. Understandably, the approach worked best with those clients and community workers who were very experienced in giving testimonies. I will discuss this further in chapter 8.

I began all the interviews, with explaining the purpose of my research and the interview, and giving the interviewee the opportunity to ask questions

about my research²⁶. Most of the interviews were recorded and I asked permission to record as part of the introduction.

Interview relations

Qualitative interviews should not only be understood as the discourse they produce, but also as a matter of interaction taking place in a particular context (Davies 2003: 99). In this section, I briefly reflect on the interaction aspects of the interviews.

My interviews with programme coordinators and well-educated counsellors were rather unproblematic and the questions I asked for the most part opened up for detailed narratives and reflections. But with interviewees who had a shorter educational background and often therefore more limited English skills I encountered some challenges. Based on my experiences in Kampala in 2006, I was expecting the semi-structured interview method to pose such challenges. I often felt I had to overcome quite a distance between me as a highly educated *muzungu* and less educated employees and I had to carefully handle the situation not to make it seem like a kind of examination of the interviewee.

Therefore, the challenge mentioned above of translating my rather abstract analytical interests into concrete, descriptive questions was even greater (cf. Kvale 1997: 135-6). The interview guides reflect attempts to do so, but I also adjusted questions during the interviews, considering how the conversation was flowing. Gradually, I learnt the familiar 'Ugandan English' way of framing certain questions as I conducted more and more interviews.

In the opening introduction to the interview, I always emphasised to the interviewee that this was not an exam with right or wrong answers and that I was interested in hearing about his or her views and experiences. However, I do not think that this in itself made a great difference. In some instances, I chose not to record interviews with community workers and clients, in the anticipation that recording the interview could exacerbate their anxiety to answer 'correctly'.

Another more important strategy I used was to identify interviewees that I had already established some contact with. For all the interviews I conducted in 2009, I conducted the interviews towards the end of my stay in the respective organisations in order to give me time to establish

²⁶ This introduction part took around 10-15 minutes. I briefly introduced the purpose of my research, the purpose of the interview, why I was interested in interviewing the person. I told the interviewee that I would ensure their anonymity, and asked permission to record the interview. I ended the introduction part with asking whether the interviewee had any questions about my research.

relationships with specific counsellors and community workers I could interview. Using this method was also the reason why I ended up interviewing few clients. I assessed that some prior interaction and familiarity would be essential for conducting a meaningful interview with clients. In Maracha's AIDS clinic and the Ediofe programme, I did not get to interact with clients in such a way that I felt I could conduct good interviews with them. But in KCCC, I interviewed a few clients that I had interacted with as part of observing counselling and home visits and that I had established a somewhat closer contact with. A number of these clients were also English speaking and that was an added advantage. The benefits of this approach for all the interviews with counsellors, community workers and clients were that I could not only conduct, but also analyse the interview as part of a broader interaction with the person (cf. Davies 2003: 94).

Focus group discussions

Like others I have had mixed experiences with focus group discussions in Ugandan settings (Rasmussen 2007a; Meinert 2001: 41). However, in June 2008, I decided to try out the method with a few KCCC employees with relatively good English skills. I organised two focus group discussions with the purpose of discussing the role of Christianity in their work in order to foreground the discussions of how KCCC defined itself as a Christian, or particularly Catholic, organisation. It was the Monitoring & Evaluation Coordinator (my main contact person) who recruited participants for these interviews based on this description of the topic. Most of the participants were counsellors (or counsellors/pastoral workers), but there was also one social worker, a young peer educator and an M&E employee.

With this group of people, and by carefully explaining 'the rules' of focus group discussions and developing various exercises (see appendix 5), I managed to generate good discussions. However, the participants' responses were in some instances more characterised by being individual answers to the questions and exercises than discussions *among* participants, which focus group discussions are meant to produce (cf. Halkier 2002). The focus group discussions, however, helped produce detailed narratives of the beginning of KCCC and discussions that spoke of a central place of Christianity in the employees approaches to care and treatment for people with HIV/AIDS. The contrast between these focus group discussions (plus some of the other interviews), and the daily practices of counselling and home visiting with regards to the centrality of Christian conceptions of AIDS care, established key insights into the way 'holistic care' was negotiated with bio-political ambitions and neo-liberal development rationalities in KCCC.

For the AIDS clinic in Maracha Hospital and the home-based care programme coordinated by Ediofe Health Centre, I did not assess that focus group discussions would be a viable method. Since most of the counsellors and community workers there have limited English skills, it would require translation and this was in my experience not easily combined with the focus group method.

Other methods: documents and simple questionnaires

In all the three Catholic organisations, I also collected a few background documents, such as evaluation reports, annual reports, constitutions etc. From the national Catholic coordinating bodies and intermediary funding organisations, I also collected such reports as well as various training manuals on HIV/AIDS education and counselling.

For the KCCC community workers I developed a simple questionnaire to help me generate an overview of the community workers in terms of gender, age, socio-economic details, religious affiliation, how many clients they had assigned and if they were also living with HIV/AIDS themselves (see appendix 6).

Negotiating access and positions

Understanding ethnographic research as a matter of immersion into a defined social setting (Emerson et al. 1995) means that acquiring some kind of meaningful position in the social setting is one of its most central features (Hastrup 2003: 10; Tjørnhøj-Thomsen 2003: 94). As argued above, my observation practices in the three Catholic organisations helped to constitute me as a researcher interested in documenting certain things, but there were also other dynamics at play. And it was other aspects of my practice, which enabled me to also establish a different kind of position and consequently other kinds of relationships with some of the counsellors, community workers and clients.

Researcher introductions

My access into the Catholic organisations was initially through ‘formal gatekeepers’. In KCCC, it was the M & E coordinator who was my initial contact, since he was responsible for coordinating research projects in the organisation. Initially, in Arua Diocese, the DFP functioned as the primary person introducing me to employees and volunteers in the various AIDS projects in the diocese. Connected to people in management positions, in combination with my identity as a *muzungu*, I believe that my position in the organisations was initially structured by the kind of expectations attached to ‘muzungu visitors’ as often being donor representative or part of evaluation teams (see also Richey 2008: 129-135). Aware of such

connections in subsequent introductions to staff members in the three Catholic organisations I emphasised my position as an independent researcher. I hoped to be able to establish good relationships with the staff by emphasising that I was not on an evaluation mission or a donor representative assessing their needs.

In KCCC, the daily morning prayers and announcements provided an opportunity for me to introduce myself to the entire staff. I introduced myself at the morning prayers, when I first began my research there in April 2008, and again when I returned in December 2008. Additionally, in December 2008, I held meetings with the counsellors and community workers to further introduce my research plans with them and discuss the practicalities with them.

For the AIDS clinic in Maracha Hospital, I was first introduced to the clinic's employees by the DFP during the initial studies in May 2008. When I returned in March 2009, I re-introduced myself to the small group of counsellors in the clinic.

The home-based care programme coordinated by Ediofe Health Centre had, at the time of my research, no avenues for gathering all the volunteers. As mentioned above, I therefore relied on the coordinator to establish contact and introduce me to specific volunteers.

Because I participated in different counselling sessions and home visits, my assistant or I had to continuously re-introduce the purpose of my presence at the beginning of sessions and home visits. Sometimes, I had to re-introduce myself to counsellors and community workers I had not previously been with, and I always had to introduce myself to the clients participating in these sessions or home visits.

In all of these introductions, I continuously emphasised my role as an independent researcher (as well as my commitment to protecting their privacy). But these instructions did not always put an end to speculations and questions about my presence as a *muzungu*, and explicit or latent expectations of my ability to offer assistance or provide access to 'a project' were almost always present. I will discuss this further under ethical considerations.

Beyond the researcher...

I spent much time being concerned about the way the purpose of my presence was introduced because I constantly had to re-introduce myself. But it is important to note that 'access' and a position in an organisation is not merely established by getting permission from formal gatekeepers and by careful researcher introduction. The counsellors, community workers

and clients were also gatekeepers to their own lives and negotiating access to their lives was a continuous process (cf. Thomsen-Tjørnhøj 2003: 104).

I came to realise that it was with time and with my willingness to be part of the counsellors and community workers' daily work and challenges that I could establish a different kind of, and closer, relationship with them. Hanging out in the counsellors' office in KCCC at the end of a busy day of counselling sessions, helping the KCCC counsellors write a monthly report, going on long days of home visits in distant corners of Kampala district and Maracha county, going with the Maracha counsellors to an all-day testing outreach of more than 100 people, were practices that helped open up for different kinds of interactions with some of the counsellors and community workers. Gradually, some of them began to share frustrations and dilemmas of their work with me, as well as details from their personal lives. Engaging in discussions of the challenges they were facing, among other things, in the preliminary feedback discussions I organised (see more below), further improved my relationships with them. In KCCC, it was also significant that mid-way through my fieldwork there I had learnt enough Luganda to participate in simple greetings and conversations. My commitment to learn the language was awarded with the counsellors jokingly giving me the Luganda name Nanyonga.

Because of my limited interactions with the community workers from the Ediofe programme, I did not manage to establish these kinds of relationships with them.

Interacting with clients

Since I primarily established contacts with people with HIV/AIDS, in the contexts of counselling sessions and home visits, in my interactions with them I inevitably had a position as someone connected to the organisation. Additionally, both as a researcher not normally part of the organisation, and as a *muzungu*, I was implicitly associated with 'donors'. This means that not only were my exchanges with them structured by how they were interacting with the organisations as 'clients', being seen as a kind of 'donor representative' meant that themes of both gratitude and appeals for assistance were dominant.

The home visits in KCCC and Maracha Hospital were as mentioned above situations where some of the broader context of clients' lives came into view. It was also primarily during home visits in KCCC, that I established a closer relationship with some clients, making it viable to conduct interviews with them. Again, committing myself in some situations as more than merely an observant researcher made a difference; some of the clients whose situation I will discuss in detail, were clients where I decided to

offer some kind of assistance and where I returned to follow-up on how they were doing (see chapter 9).

Challenges to researcher participation in counselling sessions

Despite the kind of interactions discussed above, my participation in counselling sessions and home visits were primarily as a researcher interested in documentation²⁷. For the counselling sessions in KCCC this proved to be a challenge. The counsellors in KCCC were initially hesitant towards my presence in counselling sessions. As I discussed the matter with some of them, it became clear that they were concerned about how my presence would violate the intimacy and privacy of counselling that they worked hard to establish. In this situation, it was both an advantage and at times a challenge that I have a background as a student counsellor. Though the Danish university context where I had worked as a counsellor is a remarkably different setting, I could easily identify with the emphasis the counsellors placed on intimacy and privacy. But on the other hand, I also expected that they as counsellors would take responsibility for finding an appropriate way of asking the client, at the beginning of a session, if he or she was comfortable with my presence. Initially, some of the counsellors preferred to introduce me to the client that was being counselled as ‘a fellow counsellor’. While I found this ethically problematic from the point of view of the client’s consent to be part of the research project, I realised that we had to discuss further how to find a way of making my presence meaningful in their work.

Gradually, I developed a working relationship with some of the counsellors, where they introduced me to the client as a researcher who has ‘come to learn about how we do counselling’, and emphasised that I was just as committed to confidentiality as the counsellors. The counsellors were also ‘gatekeepers’ to the kind of sessions I observed; they assessed whether the session would be one where they and the client would be comfortable with my presence. Sometimes I was informed that either the client had said that he or she would not be comfortable with my presence or the counsellor anticipated the session would be ‘challenging’ and therefore they would prefer not to have me present. There were also a few of the counsellors who never invited me to their sessions.

In the AIDS clinic in Maracha Hospital, I did not experience the same challenges. In the counselling-consultations with clients that the clinic coordinator conducted she was not much concerned with ensuring

²⁷ Adopting a position as a fellow counsellor or fellow community worker did not seem to be viable option for me, primarily because of the way my identity as a *mzungu* and especially my limited language skills would make it difficult to conduct meaningful counselling or home visits.

confidentiality and establishing intimacy. When I asked her if I could be present during these sessions, she agreed without any hesitation. Despite her different level of commitment to confidentiality and intimacy, compared to the KCCC counsellors (which I will discuss in chapter 6), her different reaction to my presence must also be interpreted in the light of the interest she possibly saw in my research providing an opportunity to address the clinic's severe resource constraints, and thereby her difficult working conditions.

Religious identity and private life in Uganda

Before beginning this fieldwork, I reflected upon the implications of my own religious identity when doing research in Catholic organisations. Based on my experiences in Reach Out, I found it useful to present myself as a Christian, despite the fact that I am a non-practising member of the Danish Lutheran-Evangelical Church. Explaining that I was a Protestant meant that I could discuss Christian conceptions of AIDS care and HIV prevention from a kind of insider position. In Catholic organisations, I found it particularly central not to rush forward with negative interpretations of their view on condoms. The question of my own religious identity was, however, not a central factor in my interactions with various research participations. What was a factor that I had to consider was that my research assistant in Kampala, Norah is a member of a Pentecostal church. In relation to the widespread suspicion in KCCC of Pentecostal churches posing a threat to their clients' adherence to ARV treatment, we had to carefully consider how she brought her own religion's identity into the interactions with clients (see chapter 9).

Another factor that I have found extremely difficult to present here is that while conducting this research I became part of a Baganda family in Kampala. Importantly, I did *not* do so for the purpose of ethnographic research. I started dating my husband Silas, whom I had become friends with in 2006, during the initial fieldwork in 2008. Our personal lives and the way I gradually became part of my new family of in-laws constitutes a much broader experience of life in Uganda (especially the Kampala setting) that I never treated as a matter of ethnographic participation. Because I have not systematically reflected upon and noted from such experiences, and since I do not actively draw upon them in my analysis, I have chosen to omit in-depth discussions of these experiences in this chapter.

Language and translation

In the three Catholic organisations and their settings around Kampala and Arua, both English and the local languages Luganda and Lugbara were used.

For the interviews and conversations with programme coordinators, most counsellors and a few clients, and for a few of the counselling sessions in KCCC, English was used. When using English in Ugandan settings, it must be clarified that a particular version of English is often used which may be termed ‘Ugandan English’, though there are regional variations. If in the following some interview quotes, statements or references to common sayings seem to be ‘incorrect’ English, it is because I generally make use of Ugandan English. I find that Ugandan English terms or sayings often illustrate important points about how a certain phenomenon or technology is experienced and perceived.

The majority of the counselling sessions, home visits and interviews with community workers and clients were conducted in Luganda and Lugbara. In these contexts, I relied on translation. Mid-way through my second stay in Kampala (mid-January 2009), I had managed to learn enough Luganda to participate in simple, everyday conversations, but it was not sufficient to conduct interviews or fully understand what was said during counselling sessions and home visits. In Arua, I asked our neighbours’ daughter, who had just completed A’levels and was waiting to start university, to teach me some basic Lugbara. Lugbara is a Sudanic language, which is rather difficult to learn because of its tonal structure and I never learned much more than basic greetings.

On a larger scale, it is clear that by prioritising a comparative focus between Kampala and Arua, I encountered somewhat greater language challenges than had I remained in one location throughout the fieldwork.

Research assistants

I hired three research assistants to assist me with translation. Through the Child Health and Development Centre (CHDC) at Makerere University, I came in contact with my assistant in Kampala, Norah Kirabo. Norah is a Musoga, but like many other non-Baganda living in Kampala she speaks and understands Luganda almost perfectly²⁸. Norah has a bachelor’s degree in secretarial studies, and had some previous experience as a research assistant from a few research projects. Norah became an extremely valuable assistant; especially in the way she helped me mediate my contact with counsellors and community workers in KCCC.

In Arua, the Arua DFP referred me to his friend Nelly Arikuru. Nelly was at that time a bachelor student in Social Works in Uganda Christian University²⁹. Nelly proved a highly skilled assistant and translator, but she

²⁸ However, she did not write Luganda particularly well. This is a skill, which in fact is rare among the Baganda as well.

²⁹ An Anglican University.

was unfortunately, at times, tied up by her new job for a small NGO. When I returned to Arua in February 2009, Nelly was so busy with her studies, her NGO job and her new role as a wife that she referred me to her classmate Jimmy Candia. Jimmy was also a skilled translator, who furthermore often took independent initiative to ask many clarifying questions to research participants. Jimmy was my assistant throughout the second stay in Arua, except for a few weeks at the end, where Nelly filled in for him, because he was busy completing his bachelor's thesis.

Consequences of using translation

Finding a way to make translation work with observations of counselling and home visits was a bit of a challenge. During the initial fieldwork in March-June 2008, I experimented with different methods of using translators when observing counselling, home visits and HIV/AIDS sensitisations. I tried to have my assistants take notes of the conversations and interactions in Lugbara and Luganda³⁰, and afterwards translate the notes into English. This method meant that while I was present I did not understand that much about what was going on (but I did on the contrary take notice of bodily gestures, seating arrangements etc.). Therefore, I eventually opted for another method. When conducting participant observations of counselling and home visits, I had an assistant with me, who quietly provided simultaneous translation of what was going on³¹.

The simultaneous translation method posed several challenges. It was a further challenge to the intimacy of counselling, especially valued by the KCCC counsellors, that not only was I present, but also an assistant, and that he or she was quietly translating to me while the session was going on. Simultaneous translation is in itself rather difficult; in the process, nuances and details are easily lost. When many things were going on and said at the same time, my assistants often provided a kind of summary to me rather than a detailed translation.

In interviews, which could not be conducted in English, I also used simultaneous translation in most cases³². This included the same challenges of possibly leaving out nuances and amounting to summaries rather than detailed narratives. The translation tended to impede the flow of the semi-structured interview; the method of asking open-ended, explorative

³⁰ However, because of Norah's limited skills in writing Luganda, she opted to take notes directly in English instead.

³¹ In KCCC, when there was occasionally a counselling session in English, (which I was invited to), I participated in that session alone, while Norah would participate in other sessions on her own.

³² In one instance, Norah conducted an interview in Luganda, and she transcribed it directly into English afterwards.

questions, and taking up themes brought up by the respondent's answers for further elaboration often proved difficult to pursue in the context of translation.

In the following chapters, the implications of translation should be kept in mind. Generally, all field notes from counselling and home visits interactions are based on simultaneous translation, unless noted otherwise. All interview quotes or references are based on recorded interviews conducted in English, unless noted otherwise.

Ethical considerations

The fieldwork was characterised by a range of complicated ethical questions, most central were questions of clients' consent to participate in the research, the need to secure research participants' confidentiality, and questions of compensation and reciprocity.

'Informed consent'

One of the challenges with my research design was how to ensure that the clients who participated in the counselling sessions and home visits I observed were aware that they were part of a research project and could get a chance to agree to be part of it or not. My concern was that in an effort to please me, some counsellors and community workers would skip or jump too lightly over the question of client consent.

Therefore, I discussed with the counsellors and community workers at the beginning of my time in the three organisations that it was essential for me that I was introduced properly to the clients. We also discussed how they could introduce the purpose of my presence to the clients. Despite the fact that I often repeated these principles just before going on home visits or being part of counselling sessions, my assistant or I often felt a need to correct or add to these introductions.

More fundamentally, the challenge was that a large part of the counselling and home visiting in the three organisations has a rather mandatory character. Much 'on-going counselling' of clients, as well as agreeing to receive community workers in your home, are required aspects of being on ARV treatment. In a preliminary feedback meeting with the home-based care team in KCCC, I discussed my concern with inadvertently making public the HIV positive status of a client who had not disclosed to household members or neighbours (see more below). The community workers generally shared my concern and agreed not to take me to clients who had not disclosed. However, the coordinator contended that 'people agree to get visitors when they start the treatment. Even white people, it may be a donor coming to visit' (Fieldnotes, preliminary feedback meeting 21 Jan 2009). In this way, I inevitably became part of asymmetrical power

relations where taking ARV treatment requires that you ‘have to agree to receive visitors’ in your home, or as in the Maracha clinic come for the regular counselling/consultations. Apart from the exception of the KCCC counsellors’ asking to the clients’ willingness to have me present, it is not likely that many of these clients would have felt in a position to decline participation in my research, despite a careful introduction of the purpose of my presence.

Anonymity and confidentiality

Throughout the research, it was central for me to ensure the confidentiality of research participants.

During the fieldwork, I was mainly concerned about confidentiality issues in the context of home visits. I was afraid that when joining community workers on home visits, I could inadvertently make public or start rumours of the HIV positive status of a person who had not disclosed to the household or his or her neighbours. This concern was derived from the attention my presence engendered and the common assumptions between ‘the AIDS industry’ and *muzungus* in Uganda. Whether in densely populated informal settlements in and around Kampala or in villages in Maracha county, my presence caused some commotion³³.

I discussed this concern with the different groups of community workers in my initial talks with them, and it turned out that most of them already took into account clients’ level of disclosure on home visits. Both the KCCC and the Ediofe community workers were remarkably concerned with protecting the individual client’s right to decide whom to disclose their HIV status to. Therefore, they agreed to keep these concerns in mind for the home visits where I came along.

Writing this dissertation, I have chosen to secure the anonymity of research participants by referring to them in pseudonyms. However, since the three Catholic organisations are not anonymized, when I refer to the position and personal details of certain employees and volunteers, they may be recognizable to insiders in the organisations. However, the pseudonyms help to blur who they are and protect them from having their name on print. For some of the people living with HIV/AIDS who have not openly

³³ When walking in urban areas around Kampala, I usually attracted a small crowd of children chanting *muzungu, muzungu*. In Maracha and Ayivu counties, groups of children would sometimes follow my car to see where this *mundu* (the common word for white person in Northern Uganda; it means rifle or gun) was going. Other times words of my presence appeared to get around a village and gradually a home visit would attract a number of bystanders (during these home visits we often sat outside).

disclosed their HIV status, I have additionally omitted some personal details to further protect their anonymity.

The three Catholic organisations have agreed to be mentioned by name. I had initially considered also keeping them anonymous in order to protect them from possible accusations about the merits of their work. But it proved difficult to do so, while also analysing significant background information about these organisations. Unless I left out significant background information about the organisations, it would be clear to those who know the organisations, which organisation I was referring to.

In the following chapters, all names of informants are thus pseudonyms, with the exception of official leaders or representatives of the organisations who are already publicly known in these professional positions (e.g. the founder of KCCC or the Arua DFP).

Questions of compensation and reciprocity

The primary way I had envisioned to ‘give something back’ to research participants was through the dissemination of research findings. I organised preliminary discussions with the KCCC counsellors and community workers, which had the dual purpose of discussing my preliminary findings and working out any challenges to my participation in home visits and counselling sessions. At the end of my fieldwork, I presented my research findings to employees in all the three organisations, and for a group of Catholic stakeholders at the Uganda Catholic Secretariat. Additionally, through the Working Group on Social and Political Aspects of AIDS in Uganda (at CHDC), I organised and participated in various seminars where I had the opportunity to discuss my research findings with other practitioners as well as Ugandan researchers.

I had decided not to offer research participants any other form of compensation³⁴, because I was concerned with reinforcing the forms of patronage, which development projects tend to produce, in the form of for example allowances (usually referred to as ‘facilitation’ in Uganda) (see e.g. Smith 2003; Swidler 2006; Swidler & Watkins 2009). Additionally, when participating in counselling and home visits, I anticipated that it would be problematic to offer clients some form of compensation for their participation in my research project, as this might create expectations of continued flows of ‘facilitation’ in future home visits and counselling. It was also the official policy in all the three organisations that counsellors and community workers were not allowed to give or receive any money or food from clients (as I will discuss in chapter 7 this policy was not always

³⁴ One exception was the focus group discussions, where I provided tea and a snack to the participants.

followed). In a few instances, however, we went on home visits to clients who were in such desperate situations that I felt compelled to offer some kind of assistance; even if I knew that this probably would not fundamentally improve their situation. In some instances, clients also demonstrated their appreciation of my visit by offering me a token of appreciation, typically a live chicken.

Despite my efforts to avoid establishing patron-client relations with my informants, it should be recognised that both researcher and informants use each other towards their own ends. With the community workers, for example, the fact that I had a car was a helpful way for them to go on home visits in distant locations. More generally, based on my experience in Uganda in 2006, I was expecting research participants to ask me for help in various ways. I was aware of the way both friendships and professional relations (as well as kinship relations) are often intertwined with giving money and other forms of material assistance in Uganda (see also Meinert 2001: 47). In this context, it was clear that many research participants assumed that I was connected to the development industry, despite my repeated insistence that I was an independent researcher and 'just a student'. While the managers in the organisations often asked for my help in connecting them with possible donors, a number of the clients I met on home visits asked me if the food support programmes that had been discontinued could be introduced. I replied to such appeals with a mixture of frustration, clarification of my limited ability to help and trying to find out if there was actually something I could help with.

Another question of reciprocity that a number of counsellors, community workers and clients brought up was what 'the outcome' of my research would be. Often I interpreted such questions from clients as masked appeals for assistance. But after a client had asked this question on a home visit with Maracha's clinic coordinator, she insisted that the question he had asked, and which she herself also wondered about, was how my research might be helpful to address the challenges of poverty, social inequalities and food insecurity, which they faced when providing ARV treatment. I felt compelled to reply that I was just 'a student', but that I would present my findings to both the management of the organisations, the Catholic secretariat and Danida and hope that they would consider these challenges in future projects and assistance.

Because of such interactions, while writing this dissertation I have been committed to trying to represent the complexities of poverty, social inequalities and food insecurity faced by both programmes and clients in making possible AIDS treatment and care.

Conclusion: analytical implications

Reflecting back on the fieldwork it is clear that I was probably too ambitious in terms of all the different insights I wanted to acquire through participant observations of counselling and home visits. At times, I think I was too concerned with getting enough 'data' at the expense of having patience enough to establish the kind of relationships, which would have produced quite a different kind of 'data'. However, concluding this chapter, I wish to emphasise the strengths and characteristics of the empirical material the fieldwork produced.

First, the empirical material, which this dissertation is based upon, consists of detailed written accounts of counselling and home visiting interactions in the three Catholic organisations. This material is coloured by the possible limited intimacy, especially during counselling sessions, brought about by my presence, extensive noting and the simultaneous translation going on.

Secondly, participating in counselling, home visiting and the everyday lives of the organisations have produced insights into the lived experiences of counselling and home visiting primarily from the point of view of counsellors and community workers. It has also produced some insights into how people living with HIV/AIDS interact with the organisations as 'clients' in the broader contexts of their everyday lives.

Thirdly, interviews with programme coordinators, counsellors, community workers and a few clients complement these insights, particularly with perspectives on how counselling and home visiting as technologies of government and of the self are inscribed into and negotiated with specific governmental rationalities.

There is in the material a greater wealth of notes and interviews concerning Kamwokya Christian Caring Community than the two other organisations. But I attempt to balance the analysis to cover all three Catholic organisations as equally as possible to allow for comparative analysis.

4. The Catholic Church and ‘the Ugandan AIDS response’

This chapter serves as a contextualisation for the analyses in the forthcoming chapters. It outlines the background of the three Catholic organisations in Kampala and Arua dioceses, by introducing the history of the Catholic Church in Uganda. The chapter focuses on the Catholic Church in these two dioceses, and on the role of the Catholic Church in social service provision, its relations to the state and lay organisations.

The chapter also provides a brief analysis of the politics and the rationalities of ‘the Ugandan AIDS response,’ focusing on the role played by various coordinating bodies and initiatives within the Catholic Church in this particular governmental field.

History of the Catholic Church in Uganda

Christian missionaries first came to Uganda in the 1870s. Anglicans from the Church Missionary Society arrived in the capital of the Buganda kingdom in 1877. The Catholic missionaries in Uganda came from three different groups. The French White Fathers arrived in Buganda in 1879, and a few years later the British Mill Hill Fathers arrived (Hansen 1984). Italian Verona Fathers (today known as Comboni missionaries) entered the Northern parts of Uganda from Sudan in the early 1900s (Cisternino 2004).

The relationship between the Anglicans and the Catholics were from the onset characterised by rivalry (Hansen 1984). Throughout the colonial era and after independence, these two churches have constituted a central religious, political and social duality in Uganda (Gifford 1998; Kassimir 1999). In terms of membership the two churches have been almost equal in numbers, with the Catholic Church having consistently slightly more members than the Anglican Church. According to available estimates Catholics constitute 40-45% and Anglicans 35-40% of the population³⁵. Islam constitutes a significant, though minor religious grouping with members amounting to 10-15% of the population. Despite the Catholics having more followers than the Anglican Church, the Anglicans have

³⁵ The 2002 national census recorded 42% Catholics and 36% Anglicans. While the 1991 national census recorded 45% Catholics and 39% Anglicans, see <http://www.ubos.org/> (last accessed 7 Jan 2011).

continuously been more centrally placed in the politics of the Ugandan state³⁶ (Ward 1995).

Since Museveni came to power in 1986, the duality of the Catholic and Anglican churches has been replaced by a much more heterogeneous ecclesiastical field in Uganda. The “near monopoly of the Roman Catholic and Anglican churches is being shaken” both by new foreign missions and a growth of local independent churches (Kassimir 1999: 249). This is reflected by a wide range of Pentecostal churches that has ‘mushroomed’ in most parts of Uganda. During my research this development was highly relevant in Kampala, but in Arua Diocese such a development was only slowly manifesting itself.

Providers of health and education

During the colonial era, the Anglican and Catholic missions in Uganda had a near monopoly on the provision of education (Hansen 1984). The two separate and competing school systems served to reinforce the rivalry between the Anglicans and the Catholics (Gifford 1998: 113). The mission-run school system was based on an agreement between the missions and the colonial administration, which meant that the missions received financial support from the colonial administration to run schools. But since the missions received no outside funding for pastoral work and evangelisation, this arrangement resulted in tensions around the prioritisation of education over evangelisation and in dealing with the colonial administration’s influence on educational policies (Hansen 1984: 237-250). This arrangement is somewhat parallel to current situations when religious organisations receive funding from foreign donors to implement development activities, which may have consequences for the pastoral or evangelizing work of these organisations (cf. Christiansen 2010). Hansen’s account is based on the Anglican CMS mission, and is connected to their specific challenges in building a self-supporting Ugandan church, however, his account illustrates a more general debate within the Christian missions of whether education and health provision should be secular activities are part of a comprehensive mission strategy of transforming Ugandan society in the direction of Christian civilization (Hansen 1984: 249-258).

Apart from education, the Christian missions were involved in the provision of health services. The Catholic Church focused on establishing health facilities in “rural underprivileged” areas (UCMB 1999: 1), in connection with mission out-stations (Orach 2005). Today, some of the most trusted and well-functioning hospitals in Uganda are Catholic, for

³⁶ This is historically connected to the closer relationship and shared national sentiments between the British colonial administration and the Anglican missionaries (Hansen 1984: 23-57)

example Nsambya hospital in Kampala, established in 1903 by Little Sisters of St. Francis, and St. Mary's hospital Lacor in Gulu established in 1959 by Comboni Missionaries. The Uganda Catholic Medical Bureau was established in 1955, as one of the first departments of the Inter-diocesan Secretariat, which later became the Uganda Catholic Secretariat (UCMB 1999). Presently, the Catholic Church has 29 hospitals, 230 lower-level health units and 12 nurse training schools across Uganda, employing about 6,000 health workers, and constituting the second largest health provider in Uganda (Interview UCMB official 25 March 2008³⁷). The Anglican Church's provision of health services is somewhat smaller, with 6 hospitals and 256 smaller health units across Uganda³⁸.

In 1997 and 1998, the Uganda Episcopal Conference (the council of Catholic Bishops in Uganda) approved a policy and mission statement for Catholic health services in Uganda (UCMB 1999). These outline the mission of the Catholic health services as "derived from the mission of the Church which has a mandate, based on the imitations of Christ and His deeds, to promote life to the full and to heal. These services are committed to a holistic approach in healing by treating and preventing diseases, with a preferential option for the less privileged" (UCMB 1999: 4). Providing health services is thus formulated as a direct continuation of the Church's mission and as an imitation of Christ. Notably the provision of health services is defined as a holistic endeavour, laying a foundation for rationalising health projects as an integration of medical, material and spiritual healing. The 'preferential option for the less privileged' is pursued by trying to offer health services in under-serviced areas and maintaining low fees for health services.

Religion-politics relations

Related to the phenomena of the Anglican-Catholic duality was also the establishment of political parties in the 1950s-60s which followed denominational lines. The Uganda People Congress (UPC) was linked to the Anglican Church and the Democratic Party (DP) is still linked to the Catholic Church. UPC won the first election after independence in 1962, bringing its leader Milton Oboto to power as prime minister, thus continuing the tendency of 'Anglican privilege'. For the Democratic Party, Kassimir argues, that lay elites and activists were central actors in mobilising popular support among lay Catholics, and the "historical situation of Anglican privilege, and the grievance it engendered among Catholic clergy and laity, was the raw material used by DP leaders to mould a political support base" (Kassimir 1998: 62). Though the coup by

³⁷ See also <http://www.ucmb.co.ug/> (last accessed 27 Dec 2010).

³⁸ See <http://churchofuganda.org/departments/health> (last accessed 27 Dec 2010).

Idi Amin in 1971 brought a Muslim to power, both the political and social importance of the mainline churches appears to have been mutually self-reinforcing during the fractional wars of the 1970s and early 1980s, and in the context of uncertainty and public infrastructure breakdown (Kassimir 1999: 252).

Since the NRM takeover in 1986, religious organisations have been depoliticised on a number of fronts (Christiansen 2010: 18). The NRM government has campaigned against the association between political parties and churches (Kassimir 1995: 121). The period of no-party rule from 1986 to 2006, has contributed to the weakening of UPC and DP and the diminishing of links between the two parties and the two mainline churches (Carbone 2008). However, DP continues to nominate candidates for elections among Catholics. The NRM government has also pushed for an ‘NGOisation’ of religious organisations in Uganda. Foreign missions are only allowed to enter Uganda if they commit to do ‘development work’ as well (Gifford 1998: 154) and new religious groups are required to register as NGOs. Finally, the relatively more open political climate the NRM government has brought is often identified as one of the prime reasons for the growth of new foreign missions and locally initiated churches from the 1990s (Hansen 2002: 173; Gifford 1998), which in effect has challenged the political importance of the mainline churches and their related political parties.

Catholic lay organisations

Catholic missionaries in Uganda initially established various lay associations under the umbrella Catholic Action, to assist in the pastoral and evangelical mission, and to socialise the laity into the values and belief of the faith (Kassimir 1998: 68-9). However, as Kassimir argues the membership criteria is wide in the Catholic Church (it is based basically on baptism) and today many Catholics engage in popular religious practices which are against official church doctrine (Kassimir 2001: 97)³⁹. There are questions about the extent to which the Catholic Church can accommodate lay groups involved in popular Catholicism (cf. Kassimir 1999). Popular expressions of Catholicism are particularly relevant for responses to misfortunes that revolve around spiritual healing and protection from witchcraft (Behrend 2007).

One forum for popular Catholicism is the Charismatic Renewal, which came to Uganda in 1973⁴⁰. The Charismatic Renewal seeks a deepening of church members’ faith through enhanced Bible knowledge, more enthusiastic and expressive forms of religious practice, a levelling of

³⁹ See also M. Green (2003) on southern Tanzania and Lado (2009) on Cameroon.

⁴⁰ <http://www.uccro.org/serviceteam.php> (last accessed 23 Dec 2010).

authority distinctions between clergy and laity, as well as an emphasis on receiving the Holy Spirit and on faith healing (Kassimir 1995: 130). In this way, the Charismatic Renewal has a potential to challenge not only what it means to be a Catholic, but also clerical authority (Kassimir 1995: 130-1; Christiansen 2010: 75). Consequently, Charismatic Renewals have been perceived as a threat by some clergy and laity and engendered conflicts within parishes (Kassimir 1995).

As a solution to the observation that many Catholics are only 'Sunday goers' (Kassimir 1995) that perhaps also participate in 'extra-formal' religious practices (Kassimir 2001), Catholic Church leaders across Africa instituted a new priority in lay organisation in the 1970s. This was the establishment of Small Christian Communities. The strategy was inspired by the base communities in Latin America, which had been central in developing and proliferating liberation theology (Kassimir 1998: 69). The ideas with Small Christian Communities were in line with the second Vatican Council vision of loosening the church hierarchy. They were "to be vehicles of Christianisation, evangelisation and socialisation from below, rather than from the top down" (Ibid: 70). Practically, lay Catholics were to organise themselves in small, neighbourhood communities, where they engaged in bible-reading, prayers and 'self-help' projects. The idea was that lay Catholics would be encouraged to take more responsibility for their own Christian formation and socialisation, leading to a form of 'spiritual empowerment', which was hoped would spill over into social and political action, as had happened in the context of base communities in parts of Latin America (Ibid. 69-70).

Kassimir argues that after 20 years of experimenting with Small Christian Communities (SCCs), the strategy has not been rather successful across Eastern Africa (Ibid. 70; AMECEA 1997). In Uganda, the Small Christian Communities have not been established as voluntary organisations, but as the lowest branch of the church's territorial administrative system to which all Catholics living in a village belongs. Therefore many Catholics perceive the SCCs as basically an administrative unit (Kassimir 1998: 71). Kassimir points out that one of the challenges with SCCs is that the goal of developing participatory values can be difficult to fulfil in an institution dominated by hierarchical structures, and that the priests themselves are not enthusiastic with the way the SCCs requires them to shift "from being the organiser of everything to being the animator and facilitator" (Ibid: 71).

Kassimir identifies one parish in Fort Portal diocese (Western Uganda), which had several active SCCs who held prayer meetings and were engaged in a variety of self-help projects. In this parish, an American parish priest of the Holy Cross Mission order had played a key role in nurturing the SCCs. Kassimir argues that as a relative outsider, this parish

priest was probably more “autonomous from the diocesan hierarchy and less threatened by the potential autonomy of these groups than local clergy” (Ibid: 71).

The Catholic Church in Kampala

The Archdiocese of Kampala geographically covers the districts of Kampala, Wakiso and Mpigi. The present Archdiocese was established in 1966, combining the Archdiocese of Rubaga (previously administered by White Fathers) and Kampala diocese (previously administered by Mill Hill Fathers) (UCS 2003: 130). Its seat is on Rubaga hill, together with Rubaga Cathedral. Presently, the Archdiocese consists of 53 parishes⁴¹. Placed in the capital, the Archdiocese is home to a large number of religious orders working with social and development initiatives (UCS 2003: 133-7). Because of their transnational personal connections, members of religious orders are often instrumental in securing resources for development and social activities (cf. Gifford 2010).

In the Kampala context, the Catholic Church is today challenged by the dramatic growth in various Pentecostal churches. Mega-churches such as Kampala Pentecostal Church, Makerere Community Church and Rubaga Miracle Center, who primarily attract a young middle class, have an extremely visible presence in Kampala (Gusman 2009). The estimates from the 2002 national census put the percentage of Catholics in Kampala district at 34%, while members of Pentecostal churches constitute 9%⁴². The percentage identifying as Pentecostals is likely to have grown since 2002.

Kamwokya parish

The Catholic parish of Kamwokya was established in 1993. Prior to this, the area was a sub-parish under Mulago parish. Kamwokya is an informal settlement, which developed in the 1970s and 1980s during the time of war and civil unrest, attracting people from all over Uganda. It is characterised by its ethnically diverse population and a vibrant informal economy (cf. Wallman 1996).

Kamwokya constitutes an exception among the general disappointing experiences with Small Christian Communities (SCCs) in Uganda. The SCCs were quite active in Kamwokya in the late 1980s and early 1990s. Kamwokya residents usually refer to the SCCs with the Luganda term *kabondo* (*kabondo* in singular, and *bubondo* in plural), which signifies an

⁴¹ <http://www.klarchdiocese.org.ug/> (last accessed 27 Dec 2010).

⁴² <http://www.ubos.org/> (last accessed 7 Jan 2011).

enduring and forceful cell⁴³. *Kabondo* members' practices of visiting sick neighbours were instrumental in developing the volunteer activities, which eventually transformed into the organisation Kamwokya Christian Caring Community (KCCC). Similar to Kassimir's example from Fort Portal, the relative success of the SCCs in Kamwokya appears linked to the influence of several Europeans; first and foremost the Irish priest, who aimed to 'activate' the SCCs, when he arrived to the sub-parish in 1987. Secondly, three Franciscan Missionary Sisters who moved to Kamwokya in 1990 were also instrumental in supporting the activities of the SCCs. These points will be elaborated in discussion of the beginning of KCCC in chapter 5.

The SCCs in Kamwokya, and the transformation of their work into KCCC, was also connected to the Charismatic Renewal, which was active in Kamwokya in the 1990s (Gifford 1998: 170). The first parish priest in Kamwokya was Christopher Kakooza. Today, he is the auxiliary Bishop of Kampala Archdiocese, and appointed by the Uganda Episcopal Conference as the Episcopal Advisor for the Renewal. It was during Kakooza's time in Kamwokya that he became active in the Charismatic Renewal⁴⁴. According to the counsellor Anthony, who is among the *kabondo* members, who became volunteers in KCCC, many of these volunteers were members of the Charismatic Renewal (Interview 2 Feb 2009). Part of the development of KCCC as an organisation consisted of training some of the volunteers as pastoral workers in the Charismatic 'School of Discipleship and Evangelisation' at the Emmaus Centre⁴⁵. The relationship between the formation of KCCC and the Charismatic Renewal was, however, not unproblematic within the parish. According to Anthony, the construction of KCCC's main building on church land (just opposite the church) was a particular contentious issue in the parish council (Interview 2 Feb 2009).

Generally, the development of KCCC in Kamwokya parish is an example of the opportunities in urban dioceses for Catholic lay organising to transform into professional NGOs.

The Catholic Church in Arua

The Catholic diocese of Arua is situated in the area today known as the West Nile Region. This region was from 1894 to 1914 the southern part of The Lado Enclave, which changed 'imperial hands' three times in this period (Leopold 2005: 10-11). In 1914, the region became part of the

⁴³ Kabondo refers to the membrane in which the jigger parasite lays its eggs inside your body. If you only remove the eggs, and not the membrane, eggs will continue to hatch.

⁴⁴ See <http://www.uccro.org/serviceteam.php> (last accessed 23 Dec 2010).

⁴⁵ A school of evangelization run by Uganda Catholic Charismatic Renewal, situated in Katikamu, Luweero district.

Uganda Protectorate and known as the West Nile district. The region consists of several ethnic groups (whose distinction and location were codified by British colonial officials), the Alur, Kakwa, Madi and Lugbara. The 'Lugbaraland' of Middleton's classic ethnography of the Lugbara (e.g. Middleton 1965; 1971) is largely equal to today's Arua and Nyadri⁴⁶ districts, where I primarily conducted fieldwork.

The first Catholic missionaries in the West Nile region were Italian Verona Fathers and Comboni Sisters. After entering from Sudan, they first built bases in Gulu and Omach in 1910-11. In 1918, the missionaries established a station in Arua town in the area today known as Ediofe (Cisternino 2004). The same year, the District Commissioner, E. A. Weatherhead also invited Protestants to Arua⁴⁷ (Ibid: 461). The Italian missionaries in Northern Uganda initially adopted the evangelising strategy of building schools, training catechists and inviting converts to live at the mission. Comboni sisters provided medical assistance on a small scale, and the missions also provided food aid and clothes (Ibid: 461-544)

The West Nile region belonged to Gulu Archdiocese until 1953, when Arua Diocese was erected. Today the diocese of Arua consists of 32 parishes and 8 deaneries.⁴⁸ In the region, a larger percentage of the population identify as Catholics than the national average (e.g. Arua District has 47% Catholics). The region is also home to a significant Muslim community, which is highly visible in Arua town, but otherwise predominantly lives in the most northwestern districts of Yumbe and Koboko (Arua District 2002). At the time of my research there was a very limited, but slowly burgeoning presence of Pentecostal churches in Arua town. The fact that the region has not seen the same dramatic growth in various Pentecostal churches as the rest of the country is most likely connected to the only recently broken isolation of the region as a result of instability and insurgencies from the 1980s to the mid 2000s.

According to the diocese's website⁴⁹ and the Diocesan AIDS Focal Person, the diocese has very active Small Christian Communities (SCCs). Among other things, the SCCs are used to mobilise people to attend the HIV/AIDS sensitisations organised by the diocese. However, unlike in Kamwokya

⁴⁶ Nyadri district is also known as Maracha-Terego district. Since the district was carved out of Arua in 2006, there have been conflicts over its name and particularly the location of the district headquarters.

⁴⁷ These were Quakers from the Africa Inland Mission, who were already running missions in Congo. CMS allowed them to evangelize in West Nile under the condition that the converts would become part of the Anglican Church (Cisternino 2004: 465).

⁴⁸ <http://www.aruadiocese.org/> (last accessed 27 Dec 2010).

⁴⁹ <http://www.aruadiocese.org/> (last accessed 27 Dec 2010)

parish, the SCCs in Arua Diocese have not organised in ways, which have transformed into larger community-based social action.

The Catholic Church has an extremely visible presence as one of the most resourceful institutions in the region. In Ediofe, which is situated at the outskirts of Arua town, the Catholic Church has its Cathedral, the diocesan offices, the Bishop's palace, two health centres (one of which is Ediofe Health Centre), a boys and a girls school, a vocational school, an orphanage, a conference centre called the Christus Centre, a youth centre and the impressive solar-powered Communication Centre, which runs two successful radio stations, and has a small internet café and professional printing services.⁵⁰

Ediofe Health Centre III is situated just opposite the Bishop's palace. It was established in 1962 by Comboni Sisters as a small aid post within the premise of the Sisters' House. In 1966 it was licensed with the government as a health centre II, and today it has health centre III status (Ediofe Health Centre 2005). The in-charge is an Italian Comboni sister and nurse, called Sr. Paula. She is in her 60s and has been in the region since the 1970s. The health centre relies on user fees, subsidies from the government and donations through Sr. Paula's connections in Italy, but it runs on a deficit (Govule 2010: 14). The health centre has about 30 employees, which includes two clinical officers and eight nurses. The in-patient department has a bed-capacity of 46 and the out-patients department sees 55-70 patients daily (Ibid. 13). In 2004, the health centre began various HIV/AIDS activities, including the home-based care programme that I have studied.

In the small trading centre Ovujo, about 30 km north of Arua, you find St. Joseph Hospital Maracha (situated in Maracha county). The hospital was started in 1953 by Comboni Missionary Sisters as a dispensary and maternity centre. In 1973, it became a hospital and was handed over to the diocese in 1974. During insurgencies between 1980 and 1986, the hospital was looted and closed down. After having been rebuilt by 'German emergency doctors' and later by the Italian NGO CUAMM, the hospital was again handed over to the diocese in 1992 (Maracha Hospital 2009: 1; 5). The hospital has a bed capacity of 200. It has 125 employees, which includes four doctors and 64 nurses. The outpatients department sees 100-120 patients daily (Interview with managers 22 May 2009). The hospital relies on user fees, government subsidies, some funding from NGOs like CUAMM and Rotary and some donations from UCMB (Maracha Hospital

⁵⁰ In contrast, the Anglican Church has struggled for the last decade to construct a new Cathedral, which was only almost finished in 2009.

2009: 13). In 1998, the hospital started doing HIV testing, and in 2005, they established an AIDS clinic.

The Catholic Church in the Ugandan AIDS response

In this section I provide a brief outline of the role of various Catholic Church bodies and organisations in the Ugandan AIDS response.

Uganda has achieved a mythical status in relation to HIV/AIDS (Allen 2006: 7). In Uganda some of the first cases of AIDS in Sub-Saharan Africa were identified in 1982, and later Uganda has become known as *the* HIV prevention success story. My intention in the following sections is not to determine what precisely caused the success in Uganda, but rather to outline the international and national politics of the AIDS response in Uganda and the role of Catholic Church in this field.

The politics of AIDS in Uganda

The basis for claiming HIV prevention success in Uganda has been a significant decline in HIV prevalence. In the early 1990s, the HIV prevalence rates were around 10-20% and by 2002 the rate had declined to around 5% (Parkhurst 2005). The fact that the Ugandan government and international actors claimed a ‘success’ based on these statistics, reflects, however, a narrow preoccupation with achieving lower prevalence rates through individual behaviour change (cf. Stillwaggon 2006). O’Manique argues that the boundaries of the Ugandan AIDS response have been tightly circumscribed by a neoliberal economic and social agenda (O’Manique 2004: 137). Within this agenda, the individual responsibility to avoid infection has been prioritised over for example addressing socio-economic conditions that facilitate the spread of HIV/AIDS, as well as targeting the socio-economic impacts of the epidemic (Ibid: 136-7). However, below I will discuss some of the politics around Uganda’s ‘success’ in HIV prevention

A feature often highlighted about the Ugandan AIDS response is the diversity of approaches to HIV/AIDS prevention promoted not only by the government, but by a wide variety of NGOs, international agencies, religious groups etc. (Parkhurst 2001: 76). This is summed up as “a strong, symbolic leadership from the top, and a “free market” of various AIDS-related interventions from below” (Richey & Haakonsson 2004: 31). Parkhurst claims that there was a lack of strong top-down direction of HIV/AIDS prevention policy in combination with an ‘NGO friendly environment’ (2001: 78). Many observers have pointed to the significance of this environment for the inclusion of religious organisations in ‘the fight against AIDS’. The lack of a strong top-down direction resulted in a broader scope for defining appropriate responses than in other countries

(Allen & Heald 2004). According to Catholic health officials, this broader scope was particularly relevant for the Catholic Church, since it allowed them to contribute positively with 'their approach', without having to be defensive (Interview 25 March 2008, see also Parkhurst 2001: 78).

Creating an 'NGO friendly environment' was also a pragmatic and strategic response by the NRM government. By maintaining state authority around the coordination of HIV/AIDS, while largely relying on international NGOs, foreign donors and local churches for implementation and financing, president Museveni has been able to take credit for the successful decline in HIV prevalence (Parkhurst 2005; Rau 2005). According to Parkhurst, the HIV/AIDS success has enabled the Ugandan government to build international legitimacy in a way that has muted international criticism around 'good governance' issues and deflected attention away from the government's military interventions in Rwanda and DR Congo (Parkhurst 2005: 576-7). The HIV/AIDS success has also helped the NRM government gain national goodwill (Ibid.; Richey & Haakonsson 2004), in spite of democratic deficiencies. The politics around AIDS thus reflects one feature of what Tripp (2004) argues is characteristic for Museveni's semi-authoritarian regime; successfully playing to international pressures and politics, while maintaining some authoritarian political practices (Richey 2005).

Structural adjustment and the privatization of health and social services

The 'Ugandan AIDS response' took shape during a time of economic recovery after two decades of civil war and public infrastructure breakdown. This economic recovery generally followed a path of 'structural adjustment,' which resulted in high economic growth rates, but also widespread privatization of health and social services (Bigsten & Kayizzi-Mugerwa 1999). In 1987, a series of 'classic' structural adjustment programmes were initiated in Uganda. 'Rolling back the state' was not as central as in other African countries, because the Ugandan government, IMF, the World Bank and other donors agreed that the Ugandan state actually needed to be rebuilt (de Torrenté & Mswesigye 1999: 10-1).

O'Manique argues that the Ugandan AIDS response must be viewed in the context of the neoliberal agenda promoted in the government's adoption of structural adjustment programmes (2004: 137). To do so, she analyses 'The Way Forward Macroeconomic Strategy 1990-1995'. This policy focused on institutional and structural reform of the agricultural sector. With regards to public spending on health and education, the policy spelled out that this had to be aligned with the priorities of fiscal adjustment. In line with the World Bank's framework for health expenditure and financing, the Ugandan strategy proposed that public resources for the health sector

should focus on preventative, community interventions rather than curative services. Curative services should be handled by the private sector or provided for a fee. Part of the policy included encouraging government hospitals to establish private wings for those who 'wished to pay' for an extra good service, as well as introducing user fees in lower-level public health facilities (O'Manique 2004: 136-9). The government was to take on a new role of coordinating the contribution to health and social services delivery provided by private and 'NGO' actors as outlined in the 'Uganda Social Sector Strategy' (Ibid. 139)

Though Uganda could boast of one the best health care system in Africa in the mid-1960s (Whyte & Birungi 2000), the insurgencies in the 1970s and early 1980s had left the public health sector in ruins (Wallman 1996: 7). The above mentioned 'structural adjustment' of health services therefore took place in an already privatised context. Prior to the introduction of user fees in lower-level public facilities in the early 1990s, one often had to pay something anyway. One often had to give the health workers 'tea' or pay for gloves, syringes or laboratory tests. Public health facilities would often run out of drugs, and at times patients were referred to the doctor or health worker's private clinic or pharmacy to buy the prescribed drug (Whyte 1998 (1992): 324-5). The proliferation of private pharmacies and drug shops were an integral aspect of this privatization, often run by health workers searching for ways to complement their meagre salaries. They became popular in the context of dissatisfaction with public health facilities for their ability to provide treatment by proxy, adjusted to the customer's pocketbook (Ibid. 326-9; Wallman 1996).

Since the 1990s, private health facilities, both for-profit and the 'private-not-for-profit' (PNFP) - which the mission facilities are known as - have taken over a greater share of health service delivery in Uganda. The public user fees were abandoned in 2001 (Yates et al. 2006), but mission health facilities have continuously had the opportunity to recover some of their costs by charging user fees. However, for Catholic (and Anglican) health facilities user fees have to be continuously negotiated with their mandate to be a 'preferential option for the less privileged'. In response to their problems with recovering the costs of running health facilities, the UCMB and UPMB began to lobby to the Ugandan government to subsidise their operations. They were somewhat successful and since 1997 the government has supported PNFP facilities (as well as government facilities) with a Primary Health Care grant (Orach 2005: 24-5).

These health sector challenges reflects the context in which the initial responses to AIDS in Uganda were more focused on individual behaviour change and 'community projects' than on comprehensive health sector initiatives (O'Manique 2004). In recent years, these challenges have also

come to constitute obstacles for scaling-up ARV treatment (cf. Richey 2005: 112-3)

Catholic AIDS policies 1986-1992

The AIDS interventions undertaken by the Catholic Church in Uganda are situated in the national context of the AIDS response presented above.

The government of Uganda established the national AIDS Control Programme (ACP), placed in the Ministry of Health in 1986 (Uganda AIDS Commission 1993: 1). ACP was to set up sentinel surveillance sites at antenatal clinics (for epidemiological surveillance), introduce blood screening, start information campaigns, and social marketing of condoms (Parkhurst 2001: 73; O'Manique 2004: 143-51). Thus, it was largely a bio-medical and behavioural approach focusing on preventing new HIV infections. The very first educational campaigns promoted the motto "Love carefully" (Seidel 1990). It was later followed by the much cited "Zero grazing" motto, emphasising faithfulness (O'Manique 2004: 148).

In Uganda Catholic Medical Bureau, a desk to deal with HIV/AIDS was set up in the late 1980s (Adupa & Odiit 2007: 2). UCMB was involved in publishing some of the very first AIDS education material in Uganda in 1987-8 (Seidel 1990). In contrast to the government's "Love carefully" motto, the UCMB brochures and posters promoted the motto "Love faithfully" (Ibid. 68-69). The Love Faithfully leaflets provided a combination of bio-medical 'real facts' of the risks of HIV and AIDS and Christian moral teachings. The leaflets encouraged people to "Respect God's Law" regarding sex, "because having sex outside marriage exposes you and your potential spouse and children to risk". The leaflet stated that using condoms only reduces risk and is also "an abuse of God's gift" (Ibid. 68). In the government's AIDS campaign, an accommodation of the kind of medico-moral discourses promoted by the Catholics leaflets took place during 1988. For the World AIDS Day celebrations in December 1988, ACP had published a new set of posters, which showed different situations of 'risky sexual behaviour' all with the message on top reading 'Thank God I said No to AIDS'⁵¹ (Ibid. 73-75).

In 1989, the Catholic bishops of Uganda published a pastoral letter on the AIDS epidemic (Catholic Bishops of Uganda 1989). The pastoral letter promoted a similar medico-moral discourse as the first leaflets. The letter had a dual focus; on the one hand it encouraged Christians to reach out to those suffering from AIDS in compassion, and spoke against the perception of AIDS being God's punishment for sin. On the other hand, it identified

⁵¹ For Janet Museveni's much debated abstinence campaign in 2006, one of these posters was reprinted.

social and moral decay – ‘economic and spiritual poverty’ – as the cause of AIDS in Uganda, because this had led to “the loosening of sexual behaviour” (Ibid. 6). Christians were therefore reminded to follow “God’s law regarding sex” as the only way to be safe from AIDS.

From a health sector perspective the challenge of AIDS was initially the overwhelming amount of chronic patients; “the hospitals were cracking under the load of people who would never get cured” (Interview UCMB official 25 March 2008). At Nsambya Hospital, the medical superintendent, a Franciscan sister, Dr. Miriam Duggan realised that the hospital had to do something in order to cope with the growing number of AIDS patients. She came up with the idea of moving the chronically ill AIDS patients out of the hospital wards and back into their home, and instead provide home-based care through outreach services. This was the inception of Nsambya Home Care, which was established in 1987 (Nsambya Home Care 2007: 4). Nsambya Home Care was among some of the early initiatives in Uganda that illustrated how treatment, care and support for people with HIV/AIDS could be cost-effectively managed in ‘resource limited’ settings. In the following chapter, I discuss how KCCC developed out of the collaboration between Nsambya’s outreach team and *kabondo* members in the Catholic parish of Kamwokya.

Catholic AIDS policies beyond the medical: 1992-2002

In the early 1990s, the notion that AIDS was an issue that could not be addressed exclusively from a medical perspective began to be prominent in Uganda, as well as in international debates (O’Manique 2004: 59). The contributions of the AIDS Control Programme were evaluated as important, but not sufficient (Uganda AIDS Commission 1993: 1). Building on the notion that AIDS is not strictly a medical issue the contributions of the ACP were problematised for having an almost exclusive medical focus; “Later it was realised that the impact of the epidemic went beyond the domain of health, and cut across all aspects of individual, family, community and national life” (Ibid. 2). In response a multi-sectoral approach coordinated by a national commission was to encourage the active involvement of “all members of society individually and collectively, with coordination at various administrative and political levels, down to the grassroot level” (Ibid. 6). By harnessing the capacities of NGOs and ‘communities’ to provide responses to the AIDS epidemic, the multi-sectoral approach was in line with the overall neo-liberal framework of health service delivery in Uganda (O’Manique 2004: 155). The Uganda AIDS Commission, placed directly under the President, was established in 1992 to coordinate the multi-sectoral response to AIDS.

The notion of AIDS as beyond the medical also affected the way the AIDS response was centrally organised in the Catholic Church. In 2001, the Uganda Episcopal Conference established the HIV/AIDS Focal Point, thereby moving the coordination of AIDS activities out of the UCMB (Adupa & Odiit 2007: 1). In the first strategic plan for HIV/AIDS activities it was stated: "In view of the multi-faceted nature of the epidemic, Uganda Catholic Secretariat recognized the need to improve the response through strengthening a coordinated approach, and whereby all Church organs participate and share information through joint planning and implementation" (Uganda Episcopal Conference 2001: 2).

With the establishment of the national AIDS Focal Point office followed an appointment of an AIDS Focal Person in each diocese, called a DFP. The role of the DFP is to coordinate the HIV/AIDS activities within the diocese. In some dioceses, for example in Fort Portal, this has led to the establishment of an office with several employees. In other dioceses the DFP position is an extra chore for a religious sister or a member of the clergy, which may not even come with access to an office or a computer (Fieldnotes 14 March 2008, DFP meeting). In other words, the role and position of the DFP differs according to the prioritization of HIV/AIDS activities within the diocese, the diocese's financial situation and the ability to attract outside funding for HIV/AIDS activities.

In Arua Diocese, the DFP is an Anglican physician who also holds the capacity of deputy health coordinator. He has a secretary and also collaborates with the health coordinator. HIV/AIDS activities under the auspices of the diocese include HIV testing services in various health centres, a USAID-supported sensitisation project, support to orphans and the two projects I have studied. All of these activities are centrally coordinated from the DFP/health office.

In Kampala Archdiocese the DFP also holds the position of health coordinator. But since many of the Catholic HIV/AIDS activities in Kampala are run by NGOs, she does not have a central role in coordinating these activities. However, the Archdiocese is involved in helping KCCC establish replicate organisations in 4 districts neighbouring Kampala district.

Conclusion

Various parts of the Catholic Church have played different roles in 'the Uganda AIDS response'. UCMB and the Catholic Bishops participated in the early information campaigns promoting a 'medico-moral' approach to HIV prevention. A number of Catholic hospitals began to provide treatment and care services in the late 1980s and early 1990s. This was made possible by the existing capacities of these hospitals, and with the

help of the international connections of religious orders and other international funding. These hospitals include, among others, Nsambya Hospital, Virika Hospital in Fort Portal, St. Francis Hospital Mulotere in Kisoro (see O'Manique 2004: 161-2) and Lacor Hospital in Gulu.

In Kampala, the international funding that came for the new 'multisectoral response' in the mid-1990s allowed community-based initiatives such as KCCC, Reach Out Mbuya and Meeting Point to flourish. In recent years, a wider section of Catholic health facilities have become involved in the context of the scale-up of ARV treatment. This is for example the case for Maracha Hospital and Ediofe Health Centre.

5. Providing treatment, care and support in Catholic organisations in Uganda - from holistic care to ARV treatment provision

This chapter introduces two of the rationalities of government most central to this dissertation. These are the rationalities of holistic HIV/AIDS care, and rationalities around the large-scale provision of antiretroviral (ARV) treatment in Sub-Saharan Africa.

I approach holistic care as a matter of framing HIV/AIDS care from a Christian perspective, which combines medical treatment with spiritual and material assistance. It is primarily one of the three Catholic organisations, which frame their approach as a holistic one, namely Kamwokya Christian Caring Community (KCCC). But I consider the relevance of the term here for all the three Catholic organisations to form a background for analysing how the scale up of ARV treatment in Uganda pose new questions for Catholic organisations about social and spiritual aspects of suffering and healing.

After outlining holistic care rationalities, the chapter considers the rationalities and technologies of government characterising the large-scale provision of ARV treatment in Sub-Saharan Africa. I conclude with outlining the potential interplay or conflict between holistic care rationalities and ARV rationalities in Catholic organisations.

Holistic HIV/AIDS care

The notion of a holistic approach to health and healing has a long history in Catholic healthcare practice (Cochran 1999) and is part of the mission of Catholic health services in Uganda (UCMB 1999). More generally many 'faith-based organisations' in African countries today frame their unique contributions to development as holistic approaches that bridge material and spiritual transformations (Bornstein 2003; Dilger 2009). A holistic approach to development problems has in fact become a bit of a buzzword, which promises to overcome limitations of specialised, targeted interventions⁵².

In the field of HIV/AIDS, the idea of holistic approaches is tied to the

⁵² 'Holistic development' is for example often used in natural resource management literature in discussions about how to promote 'sustainable development' (e.g. Loomis 2000; Osorio et al. 2005)

notion that AIDS is not merely a medical issue, but a multi-sectoral challenge including social, economic, cultural and spiritual facets. In the 1990s, holistic HIV/AIDS care was thus in line with the general international discourse on the need for multisectoral approaches (cf. O'Manique 2004). Consequently, a number of Catholic NGOs in Kampala, including KCCC, were able to grow during the 1990s and early 2000s by accessing international funding to run programmes targeting medical, social, spiritual, emotional and economic needs of people living with and families affected by HIV/AIDS. Today the term holistic HIV/AIDS care is used by a variety of organisations in Uganda⁵³. In others parts of Africa, faith-based initiatives, including interventions coordinated by the Catholic Church⁵⁴, also make use of the term holistic care. With its widespread and diversified use it is fair to ask if holistic care is merely an empty catch phrase.

However, I find that the notion of holistic HIV/AIDS care illustrates a central feature of how healing can be framed from a Christian perspective in a way that links medical healing with spiritual and material transformations. As such, holistic HIV/AIDS care holds historical parallels to the way Christian health missionaries in East Africa envisioned medical healing as part of a larger civilisation project of doing away with ignorance and poverty (cf. Vaughan 1991).

It is especially in KCCC that the employees frame their approach to HIV/AIDS as a holistic one. In KCCC the rationalities of holistic care are closely connected to how the organisation began as a Catholic lay initiative. Therefore, I begin this section with outlining how informants presented the start of KCCC and the developments of a holistic approach. I end the section with briefly considering how and to what extent similar rationalities of holistic HIV/AIDS care were relevant in the AIDS clinic in Maracha Hospital and the HBC programme coordinated by Ediofe Health Centre.

⁵³ For example TASO, Hospice Africa Uganda (started by a Catholic missionary) and Mildmay (Anglican affiliated). The organisation THETA, which stands for Traditional and Modern Health Practitioners Together against AIDS, has a "Holistic Care Clinic" in Kamwokya.

⁵⁴ For example in Zambia, the Catholic diocese of Ndola runs an integrated AIDS programme (started as a home-based care programme in the early 1990s) building on the notion that we need to care for people in a holistic perspective that combines the spiritual and the physical (Fikansa 2009; Blinkhoff et al. 1999). In the treatment & care interventions coordinated by the AIDS Office of the Southern African Catholic Bishops' Conference, the element of "holistic patient care" is stressed (UNAIDS 2006a: de Waal 2005).

The beginnings of Kamwokya Christian Caring Community

When I in the following outline the way KCCC informants framed the beginnings of the organisation, it should be noted that these beginning narratives are to some extent representations of an idealised past and also connected to how the organisation presents itself to prospective donors. The purpose of presenting these somewhat idealised narratives is to be able to analyse current debates and dilemmas in KCCC in subsequent chapters, which are tied to the organisation's perception of itself as a pioneer in holistic care. The beginning narratives are presented here in two parts; first I present the transformation of the initiatives of Small Christian Communities into a simple AIDS care intervention and then I outline how this intervention grew into an NGO with a rather comprehensive scope.

From Small Christian Communities to an HIV/AIDS care initiative

The official and often told story about KCCC is that it was established in 1987 by the area's Small Christian Communities with the support of three Franciscan Missionary Sisters for Africa, especially Sr. Dr. Miriam Duggan⁵⁵. Sr. Duggan was previously the Medical Superintendent in Nsambya Hospital and here she started Nsambya Home Care. Today, Sr. Duggan is celebrated as the founder of KCCC⁵⁶. A booklet about KCCC in the Strategies of Hope series (Williams & Tamale 1991) provides a slightly different version of events. According to this booklet, it was the Small Christian Communities that were established in the sub-parish in 1987, and then the transformation of their work into an 'AIDS intervention' took shape over the next five years.

As mentioned in chapter 4, Small Christian Communities were introduced in the 1970s by Catholic Church leaders across Africa inspired by the base communities in Latin America. The strategy to mobilise the Catholic laity to social action through everyday spiritual empowering has not been very successful across Uganda, according to Kassimir (1998). According to Williams & Tamale, prior to 1987, the Small Christian Communities in Kamwokya functioned like many of its kind in Uganda only as administrative units. The sub-parish of Kamwokya had been divided into 9 geographical zones, which were termed kabondo - the Luganda word for Small Christian Communities - and each named after one of the Uganda martyrs. All Catholics living in a zone belonged to the attached kabondo, but these people were "not organized as Christian Communities" (Williams & Tamale 1991: 20). Not until August 1987, when the newly arrived priest Father Tony Darragh, who had attended a course on 'community

⁵⁵ See e.g. <http://kamccc.org/> (last accessed 5 Jan 2011).

⁵⁶ She is also celebrated as the founder of the HIV/AIDS prevention initiative Youth Alive, which started as part of KCCC, but became independent in 1995.

ministries', introduced the idea of Small Christian Communities. The response was slow at first, but soon the number of church members becoming active in their respective kabondo started growing. In the kabondo, members would meet in each other's home once a week to pray, share Bible readings and decide on how to help neighbours in need (Ibid.).

In March 1988, a mobile team from Nsambya Hospital's AIDS clinic began visiting patients living in Kamwokya, who were too ill to attend the clinic. Since the nurses were new to the area, the newly formed kabondo became instrumental in guiding them to the patients' homes. Kabondo members also starting doing follow-up visits and referring new patients to Nsambya Hospital or the mobile team. Many of these new patients tested HIV positive in the hospital (Williams & Tamale 1991: 20-22). A person's HIV status was not revealed to kabondo members, but they soon realised that many of the sick neighbours were HIV positive. This realisation at first caused fear among them. But according to one kabondo member, they soon overcame their fears:

"At first we didn't realize that many of the people we were visiting had AIDS. And when we did realize, we started to worry that we could become infected with the virus too. But then we saw Sister Miriam touching and hugging people, and sitting on their bed. So we decided it would be safe for us as well" (Ibid: 22).

So in the Williams & Tamale account, the kabondo members' engagement with AIDS appears as a bit of a coincidence. Furthermore, Sr. Duggan comes across as an example of compassionate outreach to AIDS patients, which gave the kabondo members courage to do the same. In some presentations and interviews, such coincides of the kabondo members engagement with AIDS was glossed over; and the compassionate outreach to AIDS patients was sometimes presented as an idea that initially came from the Small Christian Communities⁵⁷.

Despite these differences and inconsistencies, what informants agreed on was the characterisation of the Small Christian Communities' as operating with a commitment to 'put the Gospel into reality'. For example:

'The Small Christian Communities were putting the Gospel into reality by helping neighbours in need. If someone in the community were experiencing a challenge, neighbours would visit and see how they could help . . . At that time HIV was growing in the country. There was a lot of fear. HIV positive were isolated, stigmatized, even relatives locked their doors. The Small Christian Communities

⁵⁷ For example in the fundraising coordinator's presentation about KCCC to the 15th AMECEA assembly on the challenges of HIV/AIDS, he said "they resolved to pray for God's wisdom and courage to confront AIDS and reach out with love, understanding and compassion to those afflicted by the epidemic" (Byansi 2005: 23).

decided to break this stigma, and started visiting people who were suffering from AIDS' (Informal talk with fundraising coordinator, 1 Apr 2008).

"These Christians within this community used to visit each other in a week to find out how they can help their friends, when they have the people who have died, there is somebody who doesn't have food . . . So, that is putting the Gospel in reality. " (Interview with community work coordinator Christine, 21 Apr 2008).

Like other informants, the community work coordinator Christine Namakula clarified that it was the coming together of these community-based enactments of the Gospel with the medical expertise of the three Franciscan sisters (among which were Sr. Duggan), who moved to Kamwokya in 1990, which came to constitute the beginnings of KCCC. Christine explained that it was via the Franciscan sisters' connection to Nsambya Hospital that they realised many of their sick neighbours were HIV positive and that was how the Small Christian Communities became involved with HIV/AIDS.

Simple beginnings: practical and spiritual help

The three Franciscan Sisters were thus instrumental in helping the collaboration between kabondo members and the mobile team from Nsambya Hospital to develop into an independent initiative. The fundraising coordinator refers to the start of KCCC as an establishment of a home-based care programme and a social support programme (Byansi 2005: 23). Damian Kansamba, one of the counsellors who started as a volunteer in the early days, emphasised the establishment of a clinic, run by Sr. Duggan; "So things started improving, improving, improving, but the clinic was the heart. Everything was rotating around the clinic. And I remember the first clinic; was, the container was under that tree" (Interview 28 Apr 2008). He explained the basic initiative in the following way: aside from the small clinic by the church there was a group of volunteers who would meet at the church every day after morning mass, divide themselves into small groups and go visit *the sick*⁵⁸, sometimes assisted by Nsambya's home care vehicle. From the clinic, they could refer to Nsambya Hospital if there was a need for it.

According to KCCC informants, when volunteers visited the sick, the focus was on a combination of practical assistance and spiritual support. Informants mentioned support like washing clothes, bathing the sick person, cleaning the house, fetching water, washing dishes and providing basic social support, like providing a mattress, beddings, cooking utensils

⁵⁸ In the following section I use the term 'the sick' to describe the people living with HIV/AIDS, KCCC was caring for. This is in accordance with how KCCC informants referred to the beginnings of the organisation. I will conclude on what the use of this term may reflect in the way of government rationalities in the end of the section.

etc. There was also a monthly collection in the church for the poor to buy basic food items. In a year this collection amounted to 400\$ worth of food in total. The food items were distributed by kabondo members, who would also decide which families were in most need of such assistance, and AIDS patients were often among the beneficiaries (Williams & Tamale 1999: 11)

In terms of spiritual support, Christine mentioned that when visiting the sick, they would ‘share a word of God’ with them (Interview 21 Apr 2008). They would ask if anyone in the household wanted to pray and then the members would lead in prayer, sometimes they would read a passage from the Bible and sing a hymn (see also Williams & Tamale 1991: 16). Praying with and for the sick was not reserved for Catholics or Christians only. Several informants mention that there were some Muslims who insisted they should also pray for them.

The kind of support provided during these home visits were often presented by informants as a matter of continuing the Small Christian Communities’ mission to enact the Gospel, often linking specifically to Matthew 25:35-36 (see also Byansi 2005: 29): “For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me”⁵⁹. Referring to this passage reflects the central material component of caring for the sick; it is by meeting basic needs in times of distress that the volunteers enact the Gospel. According to Damian, their work in those days was to implement Christian values in daily life:

“It was just the values we had in Christianity that motivated us to reach out to our people . . . there was that love, that drive, that love of Christ, you know, love one another as I have loved you . . . We would read a scripture, after reading it, then apply it in our day to day life. God is to help people, let’s go and help. It was practical, what we share is what we do” (Interview 28 Apr 2008).

Here, the early work of KCCC is presented as a practical enactment of the Christian obligation to love your neighbour. The volunteers were motivated by the scriptures to provide practical and spiritual support to those suffering around them. In line with the above points, loving your neighbour comes across as a matter of helping with the most basic facets of human existence; food, clothes and company.

The sacrament of presence

KCCC informants also defined the purpose of visiting the sick as a matter of breaking the isolation and rejection they often faced. Proscovia, a community worker, who started as a volunteer in 1987, explained: “we

⁵⁹ From the New International Bible: www.biblica.com/niv/

showed them love, because even others fear to come near, they were staying there in the community . . . nobody loved them” (Interview w. translation 13 Feb 2009). Both community workers and counsellors talked about situations where the sick had basically been left to die by their family, a phenomenon described as ‘death before dying’ (Niehaus 2007; Møller 2008). In such situations, the informants argued that the mere presence of another person could be an essential aspect of healing. Both Damian and Anthony, who were later trained as pastoral workers, talked about *the sacrament of presence*. Damian explained:

“There is what we call a sacrament of presence, for you being there is very meaningful to a patient who has been in a room for one week without a visitor. When you visit someone in a home, you have consoled, you have healed, you have changed that person’s mind and feelings. They say oh thank you for coming, since last week, I have never got a visitor. Nobody pays a visit to me, nobody! They have even stopped children to come and see me, because they will get infected” (Interview 28 Apr 2008).

Using the word *sacrament* implies that the presence of God is embodied through the volunteer’s presence and that it is the presence of God amidst suffering which helps to re-affirm the person’s worth as a human being loved by God. Another counsellor and pastoral worker, Charles Kalenjo, described this act of presence as a matter of *journeying* with the people living with HIV/AIDS: being with them and supporting them through whatever they go through; “journeying with them, knowing that they are not alone. . . despite that they’re HIV positive, we don’t look them in isolation, you know, but we journey with them, because we live together” (Focus group discussion 16 June 2008). Journeying can thus be seen as a way of referring to visiting the sick in their homes as both a practical and sacramental presence. Damian explained that at this time when they did not have so many patients, they visited the sick several times a day (Focus group discussion 12 June 2008).

Dying with dignity

In the early days of KCCC, a significant element of journeying with the sick was to assist them to ‘die with dignity’. The opportunities for medical help were few and most of the visibly ill people they visited were already in the later stages of AIDS. During the two focus group discussions I organised with KCCC staff to discuss the role of Christianity and spirituality in their work, the informants independently mentioned the same incident. They described the moment when a young woman slipped away in their hands as they – a large group of volunteers – sang hymns and broke into spontaneous prayers. Charles described the incident in the following way:

“the beautiful part of it, this girl died a peaceful death . . . I just remember . . . the words she said at the end, “now I know I’m going to Jesus, I’m going to meet Jesus . . . ” she even encouraged us that when I’m dying please don’t cry, just sing for me, because I know I’m going . . she knew that now I’m, I’ve been brought back, now . . . I know where I’m going, rather than the other time when she didn’t know where to go, she knew maybe she would be thrown . . . on the road” (Focus group discussion 16 June 2008)

Dying with dignity was about dying in peace, with the knowledge of God’s love, knowing that upon their death they will meet Christ. But also in a more this-worldly sense, the informants described it as having someone present in the moment of death and having become part of a new community after having lost connections to kin. Damian described how they had found the young girl, who was a Muslim, in the garbage dump, because the grandmother she was living with had thrown her out of her house. As Sr. Duggan and the volunteers continued to ‘treat her, give her love, and shared what they had’, the girl said one day: “I want to be like you people . . . I want to be a Christian”. She was baptised shortly before her death. Damian insisted that they had not been trying to convert her, but they “just gave the love that she required” (Focus group discussion 12 June 2008). Though the informants emphasised that it was not their mission to evangelise, Christine argues that the spiritual and physical care they provided meant that many of them “realised God” (Interview 21 Apr 2008).

A holistic programme develops

From a basic voluntary initiative, KCCC grew into a comprehensive community development organisation during the 1990s. This section provides an overview of this development, including presenting the wide scope of programmes initiated by KCCC aiming to provide holistic care.

The way the volunteers initially tried to embody the presence of God through material, spiritual and medical assistance can be seen as a holistic approach. Yet, what many informants emphasised is that the scope of holistic care developed even further from this basic start. As the volunteers journeyed with the sick, they experienced how the sick’s suffering were tied into larger social problems. They realised that their efforts to offer healing by simple medical treatment, practical and spiritual support were constrained by the patients’ worsening social situation. In the words of Christine:

“. . . this was chronic illness which didn’t have even a treatment that so many of them couldn’t work . . . many of them they do petty trade, and if they don’t work, they don’t have anything to eat, the children will not go to school, they will not pay house rent, and the moment you don’t pay house rent, they send you out of the house. . . . So many of them used to be in a no hope situation and very sick, didn’t have anything to eat in the house, and also we found it very difficult that you cannot even give treatment, because when somebody has not eaten, even the

treatment will not, will weaken . . . So all the programs you see here, we have come, those have been lessons learnt . . . on the long road we are moving on with these HIV/AIDS patients (Interview 21 Apr 2008).

This quote illustrates the way KCCC informants described the suffering of AIDS as not merely a medical problem, but a broad social, spiritual, familial and community problem. It also reflects the way all the different programmes started by KCCC over the years are all defined as initiatives, which have been developed on the basis on learning about the needs of AIDS patients by journeying with them.

One of the first initiatives was directed towards the children of the sick. According to Maria Nakayima, the coordinator of the Child Welfare programme, in those early days, the sick were mostly worried about the future of their children; ‘we don’t see any life without our children’s future’. (Informal comm. 3 Apr 2008) Therefore, KCCC reasoned that if the sick were to recover well, the future of their children needed to be addressed. Damian narrated this story:

“one of the ladies down there, she was hiding the drugs. And we said mother what’s the problem? Why don’t you take the drugs? She said, ‘I appreciate, well I appreciate all the services and I recommend your work but I can’t suffer both. I can’t suffer HIV and the pressure of my children. So I rather die other than seeing my kids suffer. Because the demand is too much, I can no longer provide, I can no longer work. The landlord is on my neck, school fees are needed, feeding and so forth’. . . . she resorted into stopping taking drugs, so it can quicken her death because she had TB . . . It was not Kamwokya’s intention that we want to pay fees for the children, no. It was an intervention to support our programme, and that’s why we, we started what we call the holistic and multi-sectoral act” (Interview 28 Apr 2008).

According to Damian, KCCC developed a holistic approach to AIDS care in order to ‘support their programme’. He thus presents helping people living with HIV/AIDS in a holistic way as a method of achieving the overall goal of prolonging their lives. In that sense, holistic care is not primarily about addressing a range of social problems in the community. However, after starting a number of social and economic support programmes for people living with HIV/AIDS, they had to grapple with questions about the wider social problems in Kamwokya and the surrounding areas.

The different programmes initiated by KCCC from the late 1980s until today include:

- A Child welfare department, including
 - Sr. Miriam Duggan Primary School (started as an informal school in the church hall)

- Kyebando Vocational Training Centre (now an independent entity)
- Foster homes
- KCCC Empowerment Cooperative Saving and Credit Society Ltd. (initially a microfinance programme, now an independent entity)
- A community mental health department
- Treasure Life Centre: A youth centre running sports activities and a Life Skills programme (conceptualised as an HIV prevention programme)
- ‘The community’: accommodation for homeless clients (5 rooms)
- A post-test club
- A clinic open to the general public
- Counselling and pastoral care
- Training of community health workers
- Home-based care
- Nutritional support
- Advocacy, Rights and Community Empowerment department (from 2006)

This list of programmes reflects how KCCC has been engaged not only in holistic care of people living with HIV/AIDS, but also in initiatives to prevent the spread of HIV and to care for orphans.

Some of the programmes started as rather impromptu initiatives. During the process of applying for funding some initiatives were formalised as programmes with objectives and goals. At the same time, many of the social and economic support programmes grew in response to the increasing demand. “The numbers went on increasing” the headmaster of Sr. Miriam Duggan Primary school said to explain why the organisation felt compelled to develop the informal school into a proper school (Interview 29 Apr 2008)⁶⁰. Apart from the primary school and the vocational training centre, an entire Child Welfare department has been established. Today, the department defines its scope as not merely helping orphans or children of people living with HIV/AIDS, but generally ‘orphans and vulnerable children’ (in line with international trends). The

⁶⁰ It was with the help of funding from SCIAF, CARITAS Switzerland and Western Union that a new primary school was built about 300-500 metres down the road from KCCC and opened in 2005.

primary intervention is still schooling⁶¹. They support 1300 vulnerable children by paying for their school fees, uniforms and scholastic materials⁶², but the waiting list for this support is considerable (Interview with Maria, 22 Apr 2008).

The development of child support programmes in KCCC reflects the basic dilemma they are faced with, does holistic HIV/AIDS care entail helping 'the whole person' or 'the whole community'? The development of the Child Welfare department reflects an engagement with social problems of the wider community, including mitigating the impacts of the AIDS epidemic. But in a general context of persistent social inequalities and growing privatization of education in Uganda the organisation is faced with an endless demand for such services.

A similar dilemma is relevant for the development of the microfinance programme. As indicated in Christine's statement above, the sick's lack of income-earning possibilities was early on defined as a key challenge for healing. There was initially an AIDS support fund, which made it possible to temporarily provide rented houses and help the sick to start 'income-generating projects', such as fish-trading, craft-making and carpentry (Williams & Tamale 1991: 11). KCCC informants often referred to this practice as 'we started giving grants'. The grants were modest: 5,000 to 20,000 shillings⁶³. As KCCC grew, the grant giving transformed into a 'microfinance department', where they provided loans on lenient terms (Interview with SACCO director, 2 May 2008). In 2004, the microfinance programme was transformed into a Savings and Credit Co-operative (SACCO). According to SACCO director Francis Sempande, this transformation was deemed necessary for two reasons: the demand for the loans was increasing and many loan takers were failing to repay their loans. The new SACCO is open to anyone residing in Kampala district, and like the development of the Child Welfare department, this reflects a movement from primarily helping people living with HIV/AIDS to attempting to address wider social problems in the community.

In 2001, the initial food support provided through church collections was replaced by an internationally funded food programme. 6,500 households affected by HIV/AIDS received nutritional supplements from USAID through the American NGO ACDI/VOCA. Additionally, the students in the

⁶¹ Other interventions include counselling, follow-up visits, meetings with parents and guardians, life skills seminars, and a foster home. In the foster home, 'mothers' are selected from the community to take in and raise orphans as their own and alongside their own children. KCCC then provides shelter and food to these mothers.

⁶² 500 of the supported children are pupils in KCCC's own primary school.

⁶³ In the mid-1990s one month's rent for a single room in Kamwokya cost from 5,000 to 25,000 shillings, depending on quality and location (Wallman 1996: 95).

vocational school (around 350) received food aid from the World Food Programme's 'Feed the Children' programme (Byansi 2005: 37). KCCC informants defined this food aid both as a matter of providing basic needs to the most impoverished clients, and as a therapeutic measure that compliments medical treatment, especially with antiretroviral treatment. However, the donors discontinued funding for these programmes in 2006. Today, emergency food aid, funded by KCCC's own means, is all that remains in terms of food support. The debates about discontinued food aid were a central theme of my research in all the three Catholic organisations and these debates will be thoroughly analysed in chapter 7.

Apart from the development and expansion of programmes to offer socio-economic aspects of holistic HIV/AIDS care, the pastoral care component also became more formalised over the years. A number of the volunteers went to the School of Discipleship and Evangelisation at the Emmaus Centre⁶⁴ for 6 months training as pastoral workers in 1990-1. These include Damian, Anthony, Charles and the community worker Joy. Anthony described pastoral counselling as a matter of 'practically passing over the love of God'. A pastoral counsellor therefore needs the skills of 'knowing who God is'. As he explained it, pastoral counselling was primarily about offering prayers; of knowing how to offer a prayer to someone in a desperate situation, about listening to the problems the person was going through, and then praying according to their needs (Interview 2 Feb 2009). Damian emphasised that pastoral counselling is not a matter of evangelising, and that it is not reserved only for Catholics; as long as "you don't reach out to someone with an intention of converting him into your faith, you can pray with anyone" he said (Interview 28 Apr 2008).

From 1993 to 1995, some of these pastoral workers went to TASO to be trained as HIV counsellors, since, as Anthony argued, they realised that they also needed "skills in dealing with people with HIV" (Interview 2 Feb 2009). Apart from offering both 'secular' and pastoral counselling, these employees also organise spiritual retreats for clients twice a year. They invite clients from all faiths, sometimes including their caretakers. On these retreats, clients are encouraged to give 'testimonies' on what 'God has done in their lives' (Damian, focus group discussion 12 June 2008).

Working as a Christian Community today

Part of KCCC's development has also been to transform from a Catholic lay volunteer initiative into an NGO who terms itself 'a Caring Christian Community'. KCCC officially took the name Kamwokya Christian Caring Community, when the organisation was registered as an NGO in 1994.

⁶⁴ A school of evangelization run by Uganda Catholic Charismatic Renewal, situated in Katikamu, Luweero district.

Transforming from a Catholic lay initiative to a NGO has entailed a shift from being based on volunteer work to employing paid staff. This development gradually began in 1993. It has also meant that all the employees are no longer necessarily Catholics. At the time of my research, a majority of the employees were Catholics (including all the programme coordinators), but there were also a number of Anglicans and a few Muslim employees.

Being a Christian Community is among other things enacted in the daily morning prayers⁶⁵. The daily morning prayers are characterised by their somewhat generic Christian appeal. They are opened with 1 or 2 praise songs accompanied by drums. These praise songs are known to Catholics, Anglicans and Pentecostals alike. After singing, the floor is open for anyone to say a prayer. However, when the praise is concluded with the Lord's Prayer (Our Father), it is the Catholic Lord's Prayer, which is said, and the Sign of the Cross is done. When the praise is over, various announcements and communications can begin.

In the focus group discussions, informants presented holistic care as the essence of their Christian community approach to treatment, care and support to people living with HIV/AIDS. Two of the counsellors for example said:

"As a Christian you need to treat him wholly, holistic care, that's what one should approach, you treat the psycho-part, the body . . . the social, the mental part, and the economic comes afterwards, at least when the mind is set, he will even appreciate the medicine, will heal him" (Rose, focus group discussion 16 June 2008).

"when we are reaching out to the sick, the approach, we look at this person we are caring for in a holistic way . . . there is a lot of needs, there is social need, there is spiritual need, there are psychological need and there are physical needs, so the approach we use on this person is to be holistic . . . so as Christians, we have been looking. . . the whole person will be collectively helped, yeah, that is our approach"(Anthony, focus group discussion 16 June 2008).

Rose and Anthony present holistic care as an approach, which aims to target *all* the needs of people living with HIV/AIDS, whether these needs are social, mental, economic, psychological, physical or spiritual. In their framing, healing requires many other things than medicine; there is a continuation with the initial work of the volunteers, which combined medical alleviation with material and spiritual assistance. But the quotes also reflect how rationalities of holistic care have a potential to expand almost endlessly into any aspect of human existence, as the expansion of programmes in KCCC also illustrate.

⁶⁵ The parish priest also conducts mass in the boardroom the last Wednesday of every month.

Concluding on holistic care

There are three points about KCCC I would like to conclude with. First, my argument is that in KCCC, holistic care constitutes an ideal, which managers, counsellors and community workers orient and position themselves towards in debates about how to provide treatment, care and support. The rationality of this ideal is that the suffering caused by AIDS is as much material, social and spiritual as medical and therefore healing must target all these aspects. The Christian obligation to love your neighbour is an important trope in this ideal.

Second, the fact that KCCC has something called a 'Child Welfare department' reflects the almost state-like character of KCCC operations. Their experiences with succumbing to endless demand for such services reflect the constraints and dilemmas of one community-based NGO trying to grapple in this way with the wider structural inequalities underscoring the suffering around AIDS in Uganda. For KCCC the dilemmas include questions about whether holistic care entails to help the whole HIV positive person or the whole community? And if the whole community is to be helped who are most 'deserving' of help?

Third, as noted in the start of the section, in reference to KCCC's beginnings and sometimes to holistic care, the informants tended to name the people living with HIV/AIDS 'the sick'. In contrast, in most accounts of recent events, informants used the term *clients* or people living with HIV/AIDS. The different terms reflect the difference between the initial response to care for sick neighbours and the current focus on people with a specific therapeutic predicament (person with HIV/AIDS) and people to be counselled (a client). But more than that, the sick may be seen to reflect a rather passive subject. A subject, who is to be assisted by virtue of suffering, but is not otherwise required or assumed to act.

In the two other Catholic organisations I have studied, the programmes of treatment, care and support to people living with HIV/AIDS were not explicitly defined as holistic approaches. Yet, in this section, I want to briefly consider to what extent and how rationalities of holistic care were relevant in these two organisations.

It is, as mentioned, the mission of Catholic health services to offer a holistic approach in healing "by treating and preventing diseases" (UCMB 1999: 1). But as the Arua DFP points out even with this potentially narrow definition of holistic care, fulfilling this commitment is "not always easy since operating the units become quite challenging with an inadequate resource envelope" (Govule 2010: 12). Limited resources are certainly a challenge for the AIDS clinic in Maracha Hospital. The medical director of the hospital Dr. Austin, and the community work coordinator Jeremiah,

argued that interventions like nutritional support, psycho-social support and home-based care were needed to make ARV treatment provision successful. Dr. Austin said that you need:

“ . . . other additional things, such that a client is able to say yes, that one went for care and now has improved, that may not be very obvious in our setting, because immunologically the person improves, but the nutritional status is poor.

Jeremiah added: *. . . any ART programme to be provided, it must have nutritional support attached to support the clients, otherwise, you might, one adherence is definitely affected because of nutrition, two psycho-social support if it's not provided for them attached to ART definitely you will fail, you're going to provide low-quality services, actually patients may not improve”* (Interview 22 May 2009).

However, because of severe human resources limitations and lack of outside funding, the hospital was currently not capable of providing such services in the AIDS clinic. I will elaborate on this situation in chapter 7. Here, I want to conclude with the characterisation of the AIDS clinic in Maracha Hospital as an organisation that recognises the need of ‘additional’ material and psychosocial services *to make ARV treatment effective*, yet they are constrained in providing such services. In comparison to KCCC, what was missing in both the management and the HIV counsellors’ accounts was the idea that a spiritual component is needed as well. The question about spirituality in counselling or home visiting was never mentioned by the informants, and compared to KCCC’s morning praise for example there was little daily presence of Christianity in the hospital.

In the home-based care programme coordinated by Ediofe Health Centre, 25 people living with HIV/AIDS have been trained to function as volunteer ‘community counsellors’ in the respective parishes where they live. The community counsellors’ two main tasks are to sensitise their communities about HIV/AIDS and provide home-based care to people living with HIV/AIDS. The coordinator of the programme, Jimmy Ariko, explained the rationale of home-based care in a way, which reflects a kind of holistic care rationale:

“because HIV has different areas of supporting, you may find that Ediofe Health Centre cannot really give full support of what the clients needs, some of these services can be got in the hospital and some of these services can also be got in the community or some can be got in these PHA groups, you find that, hands have to be joined together to support a client, so if the family members are fed of this information they can know what to do in case the client is in problem . . .

In home-based care you also have to involve the stakeholders, like the politicians, church leaders, community leaders all these people must be informed of supporting HIV clients . . . A person with HIV is not supposed to be owned by somebody . . . clients are not to be owned. They belong to the community, one will

not say this client is mine, no, because me I will not satisfy the need of a client, so it is a joined effort to satisfy the need of a client” (Interview 29 May 2008).

Like the informants in KCCC, Jimmy refers to the multifaceted needs of people living with HIV/AIDS. But in contrast to KCCC’s commitment to meet all these needs, Jimmy argues that it is unrealistic, and perhaps even detrimental, for the health centre to try to meet all these needs. Therefore, the task of the community counsellors is to inform family members of referral options and to engage community leaders in taking responsibility for supporting people living with HIV/AIDS. Here, families, politicians, church leaders and community leaders must ‘join hands’ to ensure comprehensive care and support. The rationales and techniques of home-based care in the Ediofe programme are further discussed in chapter 8.

Catholic organisations and health institutions as ARV providers

With the rapid scale-up of access to antiretroviral treatment in Uganda from 2004, many Catholic organisations and health institutions have become involved in providing antiretroviral treatment. In order to place the three Catholic organisations I have studied in the context of ‘global AIDS treatment’, in begin this section with a brief analysis of the changing rationalities around providing ARV treatment in Sub-Saharan Africa in a global context. From the global level I move to the national level, and place the three Catholic organisations in the Ugandan ARV treatment provision landscape. I conclude by outlining how rationalities of holistic care in Catholic organisations may be combined or be in conflict with the ARV rationalities and techniques.

The changing global debates on AIDS treatment in Africa

At the eleventh international AIDS conference in Vancouver in 1996, the advent of highly active antiretroviral treatment (HAART) was celebrated (Zuniga & Ghaziani 2008). For the first time, a medical treatment, which could potentially restore the health and prolong the lives of people living with HIV/AIDS, had been developed. HAART consists of a combination of three antiretroviral drugs, which inhibits the replication of HIV in different ways. Luc Montagnier and Robert Gallo, who were the first to discover HIV, explain the principle of combination therapy in the following way; “it was unlikely that its (HIV) changes would be sufficient to avoid three different inhibitors acting at different levels. The risk of emergence of multi-resistant mutants was, therefore, much lower” (Montagnier & Gallo 2008: vi). The principle of HAART can thus be said to be to maximise antiviral effect, while keeping the production of resistant strains of HIV at bay.

In 1996, at the costs of US\$ 10,000 for one year of treatment, HAART was considered out of reach for most HIV-positive people in developing countries (Kazatchinke & Fransen 2008: 36). Until around 2004, antiretroviral treatment programmes only came to developing countries as small pilot programmes outside national frameworks and strategies (e.g. Nguyen 2005 on Burkina Faso). Uganda became one of the first four pilot countries in a study to examine the possibility of providing ARV treatment in low-income settings in 1998 (Richey & Haakonsson 2004: 32)⁶⁶. One exception was the middle-income country Brazil, which, through its own production of generic ARV drugs and negotiations of price reductions with

⁶⁶ This pilot programme enlisted 900 patients on ARVs in JCRC, Nsambya Hospital, Mildmay Palliative Care Center, Mulago Hospital and Mengo Hospital (Ibid.: footnote p. 32).

pharmaceutical companies, began a provision of free ARV treatment through the public health care system in 1996 (Biehl 2007).

The question of access to ARV treatment in Sub-Saharan Africa was critical, since the majority of the world's HIV infected people live on the continent. Until the early 2000s, conventional wisdom among most Northern donors was that providing ARV treatment in Sub-Saharan Africa would not be feasible given the treatment costs and the underfunded health sectors in most African countries (Jones 2004: 396-7; Ngoasong 2009). There were also concerns that treatment would be counterproductive to prevention goals and that it constituted an inappropriate 'luxurious' intervention given African countries' more pressing poverty-related health problems. Finally, there were concerns among some donors as to whether Africans could follow a complex treatment regime like ARV treatment⁶⁷ (Jones 2004: 397-8).

Treatment activism: the right to life

In the late 1990s, a transnational advocacy coalition, lobbying for increasing the access to ARV treatment in developing countries, began to take shape (Smith & Siplon 2006). Nguyen argues that this coalition was leveraged by the 'biological vanguard' of Africans living with HIV/AIDS who had been tested for HIV and had learnt to 'testify' their experiences in the early 1990s (Nguyen 2005). This process was especially visible in South Africa, where the Treatment Action Campaign soon became the centre of treatment activism (Robbins 2008). Treatment activism was the focus of many local and international 'civil society organisations'. The medical humanitarian pioneer, Médecines Sans Frontières, was one of the organisations who took a lead, heading the Essential Drugs Campaign (Bartsch & Kohlmorgen 2007: 104).

As a counter-discourse to the donor rationales that large-scale provision of ARV treatment would be unfeasible in African countries, the premise of much of this activism was that access to ARV treatment constituted a right to life. A right that should not be denied the poor people of the world (Smith & Siplon 2006). For example, during the thirteenth international AIDS conference in Durban, the South African activist Justice Edward Cameron addressed the conference with this testimony; "I stand before you because I am able to purchase health. I am here because I can pay for life itself. To me this seems a shocking and monstrous inequity that, simply because of relative affluence, I should be living when others have died" (quoted in Kazatchinke & Fransen 2008: 37). A right to life in the form of ARV medicines was thus constituted as a remedy to the grave global

⁶⁷ In 2001, the director of USAID suggested that Africans would not be able to keep time to administer HAART regimes (Seckinelgin 2002: 127).

inequalities, which underlined the uneven access to treatment. The effects of this framing has been a pharmaceuticalisation of AIDS, which has constituted the appropriate response to AIDS as a matter of “finding new technical tools and cost-effective means to deliver care; that is, medicines and testing kits en masse” (Biehl 2008: 103).

The focus of the treatment activism was initially on the international trade regulations, which inhibited the production and importation of generic ARV drugs in developing countries. The activists managed to push for more flexibility in the interpretation of the Trade Related Intellectual Property Rights (TRIPs) agreement under WTO (Richey & Haakonsson 2004; Hein 2007). Together with UN’s Accelerated Access Initiative (Ngoasong 2009), these changes resulted in the prices of first-line antiretroviral treatment decreasing in low- and middle-income countries by more than 90% from 1999 to 2002 (Kazatchkinke & Fransen 2008: 3). Besides these price reductions, WHO included 10 antiretroviral drugs in its Essential Medicines List in 2002 (Ibid. 38). Despite these achievements, the access to ARV treatment remained limited in most developing countries. For example, in Uganda, it was estimated that about 10,000 were accessing ARV treatment in 2003 (Ministry of Health 2003a: 4). 157,000 were considered in need (Meinert et. al. 2003: 107). More resources, it seemed, were needed to make ‘universal access’ to ARV treatment possible.

The global consensus on universal access: ‘A mission of mercy ‘

The years from 2002 to 2004 saw a dramatic shift in global rationalities. Since universal access to ARV treatment was only resolved in a limited way in the realm of trade, development assistance became the means through which to ensure a substantial ‘scale-up’ of access to ARV treatment in developing countries. During 2002 and 2003, three major global funding initiatives designed to make the scale-up possible saw daylight, the Global Fund, PEPFAR, and WHO and UNAIDS’s 3 by 5 initiative. The latter initiative was a global call to make ARV treatment accessible to 3 million people by 2005. The target of 3 million was not met in 2005, but by 2008 it was (UNAIDS 2008b). The target setting is indicative of the new humanitarian rationality around ‘universal access’; that access to ARV treatment is a human right, and therefore, the international community must take urgent steps to make it possible to fulfil this human right. In 2006, UNAIDS issued a political statement, which included the goal “of universal access to comprehensive prevention programmes, treatment, care and support by 2010” (UNAIDS 2006b, item 20).

Some of the large-scale funding initiatives, which were meant to make universal access possible, have been framed in a remarkable ‘salvational’ language. When President Bush presented PEPFAR at his State of the Union Address in 2003, he said:

“tonight I propose the Emergency Plan for AIDS Relief, a work of mercy beyond all current international efforts to help the people of Africa” (US. President George W. Bush, State of the Union address, 28 January 2003).

The notion of PEPFAR as a work of mercy was recently repeated in the CBS news programme 60 Minutes, in a segment entitled ‘America’s Gift’. The segment reported how PEPFAR is saving lives in Africa, illustrated from the PEPFAR showcase Uganda. In this segment, the director of JCRC, Dr. Peter Mugenyi says about PEPFAR “there has never been a rescue mission, a mission of mercy, of this magnitude that has produced such magnanimous results”. Later in the segment, the 60 Minutes anchor Bob Simon pedagogically explains that the pills in questions are called “antiretroviral treatment – or miracle pills” (CBS 2010). The figure of ‘miracle pills’ is also central in Product RED’s branding efforts. With Product RED, consumers are encouraged to buy RED-branded products and, through the donations the companies then make to the Global Fund, to save the lives of African women and children through access to ARV treatment (Richey & Ponte 2011). A central marketing strategy has been to use images and stories of ‘the Lazarus Effect’ of ARV treatment. These stories show how ARV medicines can dramatically bring severely ill HIV positive Africans ‘back to life’, just like Jesus raised Lazarus from the dead (Richey 2009b). Thus, the humanitarian logic of ‘saving lives’ in Africa with ARV treatment is at times explicitly defined as a ‘new objective of salvation’, notably of saving others.

There are certainly parallels between the provision of ARV treatment as a form of salvation and the projects of medical missionaries during colonial times. Nguyen points to the way biomedicine extended colonial biopower by enrolling subjects into a colonial project through “the care of the self, techniques of the body, and novel forms of domesticity” (2009a: 206). He argues that PEPFAR subcontractors, American universities and French hospitals play a similar role today, through the technologies of the self which are meant to govern Africans to change their ways to remain free of the virus or to live positively with it (Ibid.). Yet, compared to how Christian medical missionaries were concerned with not only treating illnesses, but the production of new subjectivities (cf. Vaughan 1991), it is my argument that ARV treatment has a more clearly biopolitical focus in its concern with optimising life. This biopolitical concern is not necessarily easily reconcilable with Christian conceptions of holistic care which encompasses spiritual, material and medical healing.

Rationalities and techniques of ARV provision in African contexts

As the major donors are committed to ‘saving lives’ with the provision of ARV treatment, a need to demonstrate the number of lives saved has appeared. Both PEPFAR and the Global Fund produce statistics of the ‘number of lives saved’ and ‘years of lives saved’ (Nguyen 2009a: 209). These body counts are connected to the humanitarian framing of universal access and to a certain kind of accountability to donors and ‘global civil society’. Partly because of the initial scepticism there is an intensified need to demonstrate value-for-money. The way that the donor programmes measure life optimisation with enrolment rates, adherence rates, mortality levels etc. clearly reflects biopolitical ambitions to optimise life at the level of population.

However, to a varying degree, the donors also recognise a number of obstacles to saving lives with ARV treatment in Sub-Saharan Africa (e.g. Calmy et al. 2004). The governmental strategies and techniques implemented to overcome some of these obstacles are connected to how ARV treatment works as a medical technology and to the challenges of underfunded health sectors, poverty and food insecurity pointed to by the initial critics of ARV treatment provision in Sub-Saharan Africa.

As a medical technology HAART is premised on following a strict treatment regime. The pills must be taken everyday at the same time for the rest of ones life in order to avoid a rebound of virus replication (Montagnier & Callo 2008: vii). Consequently, both for the individual patient, and for the global project of achieving successful treatment outcomes, maintaining good adherence in order to avoid the production of resistant strains of HIV is critical. Because of the initial scepticism in the international community around the challenges of treatment adherence in ‘resource limited’ settings, ARV provision programmes across Africa have implemented social enrolment criteria, as well as a wide range of monitoring, disciplining and supportive techniques. Such techniques have allegedly resulted in higher adherence rates in Africa as a whole compared to North America (Nixon & Veenstra 2008: 469)⁶⁸. The techniques differ from one country to country, and from clinic to clinic, but we can identify some resemblances.

The social criteria to start ARV treatment may include having a ‘stable residence’, having disclosed to at least one member of one’s household or coming along with a treatment buddy (e.g. Richey 2011; Grøn et al. 2008). Another enrolment criteria can be to ‘perform well’ on the prophylactic

⁶⁸ However, having observed how such adherence rates are produced in everyday clinical practice in Uganda, I would read these rates with great caution.

drug septrin⁶⁹ (e.g. Whyte 2008). As a disciplinary mechanism, the ARV drugs are only provided to clients in limited doses, so that clients have to return to the clinic regularly for drug re-fill, clinical review and adherence check-ups. Doses range from two weeks at first, to 2 or 3 months when a client has proven the ability to adhere well and come on time for the drug re-fill. To teach clients the importance of adherence, most clinics have an ARV preparation education or counselling programme that clients have to 'pass', before they can start ARV treatment (e.g. Mattes 2009). To assist in monitoring and enabling adherence, some programmes have a home visiting programme, which extend the monitoring of adherence to the client's home and addresses 'psycho-social' barriers to adherence in the home setting. Finally, because of the importance of nutrition for adherence and a good therapeutic outcome on ARV treatment, nutritional support may be provided as a therapeutic supplement (see e.g. WFP 2010).

When donors, intermediary organisations and implementing partners have had to find ways of overcoming the challenges of providing ARV treatment in 'resource-limited' settings, the solutions have largely followed neo-liberal development rationalities around cost-effectiveness and sustainability (e.g. Calmy et al. 2004). The search for cost-effective and sustainable measures have led to a preference among donors for trying to tap into existing community structures and using volunteers for certain tasks such as home visiting. Human resource constraints in the health sectors have been a particularly thorny issue. MSF (Calmy et al. 2004) as well as WHO, UNAIDS and PEPFAR have proposed 'task-shifting' as a solution to human resource constraints (WHO 2007). Task-shifting entails shifting clinical tasks from doctors to clinical officers and nurses, and from nurses to nursing assistants, and counselling tasks from professional counsellors to volunteers and 'expert clients' etc.

Initially, some sustainability concerns were in fact bracketed because of the urgency that scaling-up was cloaked in (see e.g. Nixon & Veenstra 2008). ARV treatment was at first provided in vertical programmes with little integration into the health facilities operating the AIDS clinics. The large-scale provision of ARV treatment seems, however, to be entering a new phase. This was most recently reflected in the standoff between AIDS activists and PEPFAR over the cap in intake of new ART patients in

⁶⁹ When new clients register and they are not yet eligible to start on ARV treatment, they may be given septrin. In some clinics septrin is given for one or two months at a time, and clients are told to take the medicine every day at the same time, in this way mimicking how ARV medicine is provided and to be taken. When clients appear to manage these requirements well, they are considered ready for ART.

Uganda⁷⁰. In the shift from an urgent humanitarian mode to a more long-term consolidated intervention mode, strategies of ‘integration’ and decentralisation have become central. In Uganda, I found this shift, among other things, to be reflected in the changes in WFP policy on the provision of nutritional support to people living with HIV/AIDS.

The Ugandan ARV treatment provision landscape

The three Catholic organisations do not merely operate in the context of the global rationalities outlined above, but also in a particular national context. Considering the national context illustrates how the complex mix of different funding programmes and implementing organisations meant to ensure ‘scale-up’ in Uganda help produce an uneven landscape of access, drugs and services provided. Also significant for the Ugandan context is the relatively great influence of PEPFAR.

From 2003 to today, the access to ARV treatment in Uganda has increased from 10,000 to about 200,000 people on the treatment. PEPFAR has been one of the major donors of the ARV treatment scale-up, since the Global Fund until recently had suspended all funding to Uganda in the wake of a huge corruption scandal (Global Fund 2005; 2009). Uganda has been the largest recipient of PEPFAR funding, totalling over 1.2 billion dollars from 2004 to 2009 (PEPFAR 2010). PEPFAR has channelled funding to various Ugandan organisations and health facilities through intermediaries such as USAID, Centre for Disease Control (CDC) and Catholic Relief Services (CRS). One of the major recipients is the former military clinic and research institution Joint Clinical Research Centre (JCRC). PEPFAR, through USAID, teamed up with JCRC in December 2003 to begin the “Timetable for Regional Scale Up of ARV Therapy” (TREAT), which was to help expand access to ARV treatment across Uganda. PEPFAR funding priorities include a preference for funding faith-based organisations. Many Catholic organisations and health facilities have in this way been able to initiate ARV treatment programmes with the help of PEPFAR funding, for

⁷⁰ In early 2009, PEPFAR informed Ugandan implementing organisations to cap their intake of new patients. In the spring of 2010, news of Ugandans being denied ARV treatment and put on waiting lists circulated in the international media. These stories were part of a campaign by various African AIDS activists against ‘donor-backtracking on health funding’. This campaign was primarily directed at the American public and included the 60 Minutes segment and 3 articles in the New York Times (Richey 2010). The campaign was effective to the extent that PEPFAR in July 2010 reversed the previous treatment cap and promised to return to the previous rate of new patient enrolment (approximately 3000 new patients each month) until 2013 (Health GAP 2010).

example, KCCC, which began to provide ARV treatment in September 2004.

The Ugandan Ministry of Health also has its own ARV programme. In this programme, ARV drugs and other funding is channelled from the Ministry of Health to government health facilities, and also to some mission facilities (Orach 2005), which for example is the case for the AIDS clinic in Maracha Hospital. Since mid-2005, all government hospitals and level 4 health centres have provided free ARV treatment (Whyte et al. 2010: 84).

My fieldwork in different Catholic organisations highlighted the national inequalities in access, and the drugs and services provided. The PEPFAR funded projects seemed generally better endowed than the government-funded. In the PEPFAR-funded KCCC, primarily brand ARV drugs were provided⁷¹. In the Ministry of Health-funded ARV treatment programmes I have studied, Maracha Hospital and the government-run Arua Hospital, the drugs were all generic drugs from India⁷². Another difference is the eligibility criteria for initiating ARV treatment. At the time of my fieldwork, clients in PEPFAR-funded programmes were to begin ARV treatment when they had a CD4 count of 350 or below. In programmes funded by the Ministry of Health, clients were to begin treatment at a CD4 count of 250 or below (as of March 2009, when it was changed from 200).

Though the reports of ‘lives saved’ from funding bodies and operational research give the impression of evenly distributed ‘miracle pills’, there are thus differences between the specific types of medicines, and combination options, provided in different projects within Uganda. There are also differences in access to diagnostic technologies, such as CD4 counting and viral load measuring (see Meinert et al. 2009) and importantly human resources.

⁷¹ At the time of research, KCCC provided the brand combination pill Truvada (emtricitabine and tenofovir) with either Efavirenz or Nevirapine as first-line treatment. For second-line treatment one option was Aluvia with Combivir (lamivudine and zidovudine), but they also provided other combinations dependent on the client’s medical history.

⁷²At the time of research, Maracha Hospital, which only provided first-line ARV treatment, provided the generic combination pill Duovir-N (lamivudine, zidovudine and nevirapine), or Combivir with Efavirenz for those who are on TB treatment. In Arua Hospital, they provided among others, the generic combination pills Triomune (stavudine, lamivudine and nevirapine), and Duovir-N as first-line treatment. The use of Triomune has since been discontinued in government facilities, because of the side effects associated with stavudine.

Conclusion: Holistic care and ARV treatment

Considering the global concerns with treatment adherence, cost-effectiveness, sustainability and feasibility when providing ARV treatment in Sub-Saharan Africa, Catholic organisations, such as KCCC, Reach Out and Nsambya Home Care already committed to ‘holistic HIV/AIDS care’ had advantages to play on. Indeed, these organisations were some of the first to access PEPFAR funding in Uganda. With a community-based structure, and a large volunteer base, these organisations could fulfil sustainability and cost-effective requirements, as well as the PEPFAR requirement to focus on abstinence and faithfulness in their prevention programmes. With a broad set of interventions targeting social, economic and spiritual aspects of suffering, they could address a range of ‘psycho-social’ barriers to treatment adherence. For KCCC, the history of starting as a home care initiative was relevant for the new technique of using home visiting for ARV treatment monitoring.

During my internship with the microfinance department in Reach Out in 2006, I was left with the impression that in Reach Out the provision of ARV treatment was productively combined with holistic care rationalities. In KCCC, an incorporation of ARV treatment into holistic care rationalities was also evident in some of my interviews with programme coordinators. They argued that because of the complexity of taking and adhering to ARV treatment in impoverished settings an integrated, holistic approach, which also targets social and spiritual factors, is still highly relevant. However, as the following chapters will show, such holistic care rationalities have to be negotiated with the bio-political ambitions and neo-liberal rationalities characterizing large-scale ARV treatment initiatives.

Some Catholic scholars have been extremely critical of the rush towards making ARV treatment possible in Africa (e.g. Czerny 2007; Katongole 2007). Katongole argues that the Catholic approach should not only be one that celebrates new advances in medical technology, but a pastoral ministry, which engages “the slower, less fashionable, step by step efforts to address Africa’s problems in a holistic fashion” (Katongole 2007: 119). Czerny points to a tendency for well-funded professional ARV programmes run by Catholic health centres or NGOs to neglect some of the core functions of the church. He asks whether “the bigger, better-endowed ART programmes recognize their own limitations and seek out the Church to complement their medical services with communal and spiritual ones?” (Czerny 2007: 102).

In a context where the increasing access to ARV treatment potentially transforms the experience of living with HIV/AIDS in Uganda from a death sentence to a chronic condition requiring careful management, the questions of how the relationship between rationalities and technologies of

ARV treatment on the one hand and holistic care rationalities on the other hand are worked out in the three Catholic organisations is a key theme in the following chapters.

6. Counselling, Positive Living and ‘the rules’ of ARV treatment

Introduction

With the scale-up of ARV treatment in Uganda, counselling has become more important, not only as an integral part of testing for HIV, but as a new central arena for governing the conduct of people living with HIV/AIDS. In this chapter, I focus on practices of counselling in KCCC and the AIDS clinic in Maracha Hospital, in order to investigate counselling in clinical settings⁷³.

For counselling in the context of ARV treatment, ideas around ‘living positively’ with HIV/AIDS are being transformed. As experienced in the Catholic organisations, Positive Living is on one hand thought of as a counter-discourse to the association of AIDS with imminent death, in which the continued life potential after testing HIV positive is emphasised. On the other hand, ‘living positively’ has come to constitute a set of rules of conduct that people with HIV/AIDS are encouraged to follow. Positive Living has increasingly come to denote the healthy lifestyle choices that it is now considered a necessity to promote among people with HIV/AIDS for the sake of successfully saving lives with ARV treatment.

In KCCC and the AIDS clinic in Maracha Hospital, the practices of counselling are characterised by a similar contradiction. On the one hand, the method of counselling is premised on enabling the individual’s self-government according to autonomy, choice and inner truth. In the Ugandan context, this is often referred to as ‘counsellors are not supposed to give advice’, but give information to help people ‘make their own informed decisions’. On the other hand, the counsellors in the two clinics are generally committed to the bio-political ambitions of prolonging life with the help of ARV treatment and preventing further spread of HIV, which means that to them some ‘informed decisions’ are obviously better than others.

In this chapter I first investigate the practices of counselling in KCCC and the AIDS clinic in Maracha Hospital along these two interrelated contradictions. First considering the contradictions of counselling and then of Positive Living. In the final section, I analyse how these contradictions,

⁷³ The home-based care programme coordinated by Ediofe Health Centre will in turn be discussed in chapter 8, which focuses on home visits.

in the context of the ARV rationalities and techniques discussed in the previous chapter, pushes counselling more towards moralized teaching sessions. In these teaching sessions the clients are taught to follow predetermined rules of conduct, rather than exploring individualised possibilities and choices for actions. In this process, Positive Living is recast as rules of conduct that clients are required to follow. The chapter argues that, with regards to ethical subject formation, the counsellors help produce the notion that to live well with HIV/AIDS is to follow ‘the rules’ of Positive Living and ARV treatment.

This analysis concerns one aspect of how counsellors and community workers in the three Catholic organisations are engaged in trying to promote a certain kind of responsible self-government among people living with HIV/AIDS. The two following chapters will deal with other aspects of such governmental concerns.

Counselling methodology and practice

This section presents an overview of counselling practices in KCCC and the AIDS clinic in Maracha Hospital. The conditions the counsellors work under in two clinics differ, and throughout this chapter, these differences will be highlighted with regards to how the contradictions of counselling and Positive Living are worked out under different conditions.

I begin this section with an overview of the practical and spatial organisation of counselling in KCCC and Maracha Hospital. Afterwards, I position the contradictions of counselling experienced in the two clinics with a view to how counselling as a global technology is translated by the counsellors in the context of bio-political ambitions.

Counselling in Kamwokya Christian Caring Community

Under KCCC’s Primary Health Care department, KCCC has a clinic, community health workers and counsellors. The clinic has four doctors, ten nurses and offers clinical services both to clients and the general public⁷⁴. According to the coordinating doctor about 50% of the patients seen in the clinic are people living with HIV/AIDS (Interview 25 Apr 2008).

Three of KCCC’s counsellors have worked there since the early 1990s, and were previously trained as pastoral workers. Five were recruited in 2004 upon the start of the ARV treatment programme and one had been recruited later. Three of the recently recruited counsellors are rather highly educated: Jagwe has a bachelor’s degree in Adult & Community Education, Daniel a teaching degree, and Esther was studying for a bachelor’s degree in

⁷⁴ ‘Clients’ pay a consultation fee of 1,500 shillings, whereas other patients pay 5,000 shillings.

counselling. The other recently recruited, Rose, Olga and Elisabeth have completed O'levels or A'levels, and have diplomas or certificates in the administrative field. All the counsellors have done their HIV counselling training in either TASO or AIDS Information Centre⁷⁵, in courses ranging from 6 months to several years.

In KCCC's main building, the clinic, the lab and some pharmacy functions are placed on the ground floor, and on the first floor the counsellors have a tiny office opposite the 'ART pharmacy'. In the office, the counsellors keep all their files, and here the counsellors have their breaks. This office is also where clients most often are referred to if they want to see a counsellor. However, counselling sessions are supposed to take place elsewhere: on the ground floor, outside and behind the building there are four 'booths' designated for counselling sessions.

In the beginning of 2009, KCCC had about 1,500 clients receiving ARV treatment, and about 4,000 clients on general care, i.e. not yet on ARV treatment⁷⁶. KCCC provides both first line and second line ARV treatment. In KCCC, clients are eligible for ARV treatment when they have a CD4 count of 350 or below. . As mentioned in the previous chapter, the standard in most ARV programmes is that the drugs are only provided in limited doses, so that clients have to return to the clinic regularly for drug re-fill and follow-up. In KCCC, clients receive the ARV medicine in doses from one to three months. When they come for 'their appointment', they see their assigned doctor and pick up a new batch of drugs. For every consultation in the clinic, they pay a fee of 1,500 shillings⁷⁷, and this fee is all they are required to pay, regardless of what other medicines or treatment they get from the clinic.

The counsellors in KCCC handle both counselling in connection with testing and on-going counselling of clients. Some of the counsellors are specialised in handling certain clients; two are trained as child counsellors and one is trained to handle rape victims. The pre- and post-test sessions are always individual or couple sessions. In the pre-test sessions, the counsellors ask clients about HIV transmission routes, ways of preventing

⁷⁵ AIDS Information Centre is an NGO started in 1990. It is the largest and oldest VCT provider in Uganda and also a major provider of VCT training in Uganda, see <http://www.aicug.org>

⁷⁶ Clients not yet on ARV treatment are not registered to the same extent as those on ARV treatment, so the numbers are harder to determine, but they were said to be about 4,000.

⁷⁷ 1,500 Uganda shillings is equivalent to 75 US cents. In Kampala, during the time of research, with 1,500 shillings, you could buy for example one kilo of posho (for maize porridge) or half a kilo of sugar. Poor households living in slum areas like Kamwokya may have 1,500 to 2,500 shillings to live on per day (Rasmussen 2007b).

HIV, the difference between HIV and AIDS and explains the possible test results. They also ask the client what result he or she is expecting and what he or she will do if the results are negative and if they are positive. In the post-test session, before giving out the results, the counsellor may ask the client how he or she is feeling, and ask again what he or she 'plans to do' respective of the result.

If the client tests positive, they are registered as 'a client' and an appointment to do a CD4 cell count is made. The counsellor handling the pre- and post-test session will be the client's permanent counsellor from then on. The client's CD4 count will determine whether the client is ready to start ARV treatment or not. According to Olga, they also make an appointment for supportive counselling to discuss 'the new life' the client is beginning (Interview 5 Feb 2009). Yet, I never encountered such sessions. What I did experience were sessions where the counsellor filled out an 'HIV Care Enrolment Form' with a new client.

There are different types of 'on-going' counselling of clients. One type of on-going counselling is provided in connection with the regular CD4 cell counts. If the CD4 cell counts are still above 350, the counsellor discusses with the client what he or she can do to keep them high. If the CD4 cell counts are below 350, the client is informed that it is time to start ARV treatment and the implications and requirements of the treatment are discussed. The client is then sent to an 'ART enrolment session'. The ART enrolment sessions are only conducted by Jagwe; they are group sessions where Jagwe goes over how ARV treatment works, how the treatment is to be taken, possible side-effects and what clients can do themselves to help make the treatment effective. The clients receiving ARV treatment are supposed to see a counsellor every third month to fill the 'check-list' form, which constitutes a kind of on-going session. More loosely structured on-going counselling sought out by the clients was not something I encountered, although some of the counsellors alluded to its existence.

Counselling in Maracha Hospital AIDS clinic

The AIDS clinic in Maracha Hospital only has one permanent employee, a nursing assistant/counsellor, called Joyce. When I first visited the clinic in May 2008, another nurse was also attached⁷⁸. The nurse and the nursing assistant were trained as HIV counsellors in the mid-1990s by TASO⁷⁹. In addition to Joyce, a number of 'interns' who had recently completed certificate courses in counselling in Arua were attached to the clinic. The

⁷⁸ This nurse was transferred to another ward due to general staff shortages in the hospital.

⁷⁹ During this time, TASO was involved in starting up the AIDS programme in Arua hospital.

interns had been retained on the promise that they would receive some kind of remuneration for their work⁸⁰.

The intern/volunteers handle all aspects in the clinic having to do with testing for HIV ('Voluntary Counselling and Testing'); registering people for testing, giving pre-test counselling in a group session, and communicating the results individually in post-test counselling. A lab technician is also attached to the clinic and he handles the actual testing of blood for HIV anti-bodies. The nursing assistant/counsellor, Joyce, handles everything to do with 'clients' receiving treatment. Except in the case of more complicated medical complaints, which are referred to the doctor on call or the clinical officer in the outpatients department. On Tuesdays and Fridays, the clinic is open for VCT and clients on treatment. On Thursday, there is a special Prevention of Mother-to-Child Transmission programme where all women coming for antenatal care are tested for HIV. During each clinic day, Joyce sees between 10-20 clients in sessions that include both clinical consultation, counselling and drug dispensing. In 2008, I observed an on-going group counselling session organised for clients, but when I returned in March-May 2009, the only on-going counselling clients received was the counselling that was part of Joyce's consultations.

The clinic has a waiting area with a few benches; here people coming for testing are registered in a Ministry of Health testing register. To the right is a room, which serves as both storage and group counselling room (for pre-test counselling). In front of the benches is 'consultation room 1' where the doctor on call sits if he is around, and to the left of this room is 'consultation room 2', which is where Joyce sees clients on treatment. The small lab room, where the blood for testing is drawn and the testing is done, is placed to the left of the waiting area.

The clients receive the prophylactic drug septrin⁸¹ and ARV treatment. As of March 2009, the clinic had 100-120 registered clients, of which 60-70 clients were receiving ARV treatment. The clinic only provides two types of generic first-line ARV medicine, and they cannot do CD4 cell counts. For CD4 cell counts and second-line treatment, clients must go to Arua hospital. Being part of the government's ARV programme, clients are eligible to start ARV treatment when their CD4 count is 250 or below. In Maracha Hospital, the clients get medicine covering one or two months, regardless of whether they are on septrin or ARV treatment. When the one

⁸⁰ However, the only pay they essentially received was the 'facilitation' of 8,000 shillings they received every time they went on a testing outreach, which they usually did 3-4 times in a month.

⁸¹ Septrin (a brand name) is the widely used name in Uganda for the antibiotics combination co-trimoxazole, which is used as prophylactic treatment to HIV positive patients to prevent opportunistic infections.

or two months have elapsed, clients are supposed to come back for ‘their appointment’, and collect a new batch of drugs. Every time the clients come for a consultation, they are supposed to pay a fee of 2,000 shillings⁸², or 1,000 shillings for children. However, this is quite negotiable.

Pre-test counselling is provided in a group session by one or two counsellors. The sessions follow the rather standard format of going over HIV transmission routes, ways of preventing HIV, the possible results of the test and sometimes some recommendations on what to do if the test results are positive. The counsellors also ask the clients why they wish to be tested, which in this group session context mostly produces standard replies such as ‘I just want to know my status’. The test results are given individually. Here, the counsellor again asks the client about the reason for wanting to be tested, and then gives the results. Those who test positive are ‘directed to Joyce’s dispensing room’ (Interview with Simon 12 May 2009).

It was Joyce’s counselling-consultations of clients that I devoted my time in the AIDS clinic to. When a client tests positive, Joyce has a longer session with that person (this will be discussed in more detail later), but usually her sessions last 10 to 15 minutes. They follow this format; first, the client is weighed. Then Joyce asks the client how he or she is doing, and enquires to any medical complaints. If the client needs to see the doctor or the CO, the client goes there first. Then Joyce usually asks how the client has been taking the drugs, and discusses any problems in connection therewith. Afterwards, she may briefly ask to the testing of a partner or the client’s children, or to problems in the home. The session ends with Joyce dispensing the ARV and septrin pills along with other drugs the doctor or CO may have prescribed⁸³, she informs the client of his/her next appointment, and then sometimes gives some general advice.

Counselling contradictions

Counselling is one of the central practices disseminated within the global assemblage around HIV/AIDS. As a technology, HIV counselling has been implemented in diverse settings in largely standardised ways with an assumption of stability and predictability across different environments (Nguyen 2009b: 360). Yet, as this chapter will show, practising HIV counselling in Ugandan settings requires considerable ‘translation work’.

⁸² 2,000 Uganda shillings is equivalent to 1 US dollar. At the time of research, for 2,000 shillings you could buy 2 kilos of onions or tomatoes at the market in Arua. A 50 kg sack of cassava (the primary staple food in this area) cost about 20,000 shillings at this time.

⁸³ For some common ailments, e.g. malaria, Joyce sometimes prescribes medicine without a doctors or clinical officer’s diagnosis.

In UNAIDS' Technical Update on HIV counselling, it is defined in the following way;

"HIV counselling is a confidential dialogue between a client and a counsellor aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. A counsellor is a person trained in the skills of the job: listening to the client, asking supportive questions, discussing options, encouraging the client to make his or her own informed decisions, giving practical information and suggesting follow-up" (UNAIDS 1997:1).

This definition illustrates how HIV counsellors are assumed to play a rather neutral role in enabling clients to reach 'informed decisions' about how to live with HIV/AIDS. The definition illustrates a commitment to non-directive counselling methodology, which stipulates that the primary role of a counsellor is not to take decisions *for* clients or encourage particular actions among clients, but to increase clients' capacities to make *their own decisions* (cf. Bond 1995: 20-21).

In the Ugandan context, such non-directive principles of counselling are generally translated into an almost stubborn insistence that counselling is not about giving advice. For example, during the first national HIV counselling conference in Uganda in May 2009⁸⁴, the director of the Uganda Counselling Association, reminded the audience: 'when people come in wanting advice, you have to stress we counsellors, we don't give advice!' (Ochieng 2009). Though this insistence may seem contrary to popular perceptions, as a former student counsellor I readily interpreted such statements as rehearsals of non-directive counselling methodology.

Many of the counsellors in the Catholic organisations spoke of counselling methodology in similar terms, stressing their supportive role in enabling clients to make their own informed decisions. In my interviews with the KCCC counsellors, they all talked about how they as counsellors are not supposed to give advice. Elisabeth for example said;

"Sometimes you can see that probably they want you to give advice, but a counsellor I'm not supposed to give advice, but then they would say like whatever you are saying, you tell us [interviewer laughing] . . . you give options and you can see, probably if you are not the one giving options, you want them to see the different options like giving them to you, but then they want you to advise them, which is not proper, and which I don't do, really, because I want them to find out" (Interview 12 Feb 2009).

Elisabeth's statement reflects the insistence that clients have to 'find out' for themselves different options for actions and choose between them,

⁸⁴ The conference was funded and organised by the PEPFAR funded SCOT project. SCOT stands for Strengthening Counsellor Training and primarily works with developing and harmonizing curricula for HIV/AIDS counsellor training.

rather than the counsellor giving them directions for action. During sessions, the counsellors sometimes even communicated to the clients that the purpose of counselling was not to convince them to behave in a certain way, but to encourage them to take responsibility for their own lives. Jagwe for example said to a young woman during a pre-test session: ‘as counsellors we are not trying to convince people. We give you information and you decide what to do’ (Fieldnotes 17 Dec 2008). In Maracha Hospital, Joyce similarly insisted that ‘the clients take their decision, you give them options, and then they choose’ (Arua feedback meeting 18 May 2009).

Some of the counsellors further explained that giving advice or ‘just telling people what to do’ was not only a discouraged counselling method, it was also ineffective. Charles for example explained;

“There was a lady, actually in the beginning when I had just started counselling, a lady came and said that I’m positive, and (I) said that . . . you can do away with men and all this and the woman said ‘yes I can do it’, but after a certain period this woman came when she’s pregnant and said ‘you see counsellor, nature, nature demands’ so I felt that I could not, then I realised that yes what do we need to help these people is just to tell them the consequences that they can go through” (Interview 13 Feb 2009).

In other words, Charles concludes that if you just tell a client what to do, the decision does not come from her, which means that when you are no longer there as a counsellor, the person may not follow your recommendations. What is central according to Damian is that,

“your client is willing to share his or her life experience, because the moment someone is willing to share his or her life experience you get to know her more and see where you can help, if someone doesn’t let you know him or herself, then it will be difficult where to help, where to support” (Interview 19 Jan 2009).

The way these counsellors discussed counselling methods, reflects how counselling like other ‘psy’ technologies (Rose 1998) is based on enabling self-government according to ‘the truth’ of the self, which is produced in confessional acts. Counselling techniques such as probing questions, mirroring, offering interpretations of the clients’ problems and asking to possible solutions (see e.g. Hampton 1992: 30-1; CDC 2007: 13) are precisely meant to help the counsellor understand the client’s problems and situation from his or her perspective. More precisely, the counsellors’ statements reflects how the aim of counselling is to enable responsible self-government by making the client realise capacities within him or herself, which he or she can use to overcome problems or handle everyday management of living with HIV/AIDS. As defined by TASO, counselling “supports clients to take responsibility for their lives, rather than looking upon themselves as ‘victims’” (Ssebhanja 2007: 45).

What may seem contradictory is when counsellors want to 'responsibilise' the client in a certain direction: the decisions should come from the clients, but some decisions are in the context of AIDS treatment better than others. The notion of 'informed decisions' obscures a fundamental premise of most counselling. When counselling is provided as part of programmes of conduct, there are often explicit goals for the counselling to affect a certain kind of subject formation or certain kind of conduct (cf. Brownlie 2004). As the KCCC counsellor Anthony clarified; "it's a work of a counsellor to help this person towards making an informed decision, which may lead this person to good life." (Interview 3 Feb 2009). With Foucault's notion of pastoral power, we can say that the counsellors attempt to guide the individual towards specific objectives of 'salvation'. For the counsellors I interviewed it was noticeable how they defined and evaluated their own work according to the objective of prolonging the lives of people living with HIV/AIDS and preventing further spread of HIV.

In the interviews with the counsellors, I asked them what made them happy or satisfied in their work as counsellors. All the KCCC counsellors spoke of the satisfaction with seeing their clients improving and coming back to life. Anthony, for example, said;

"What makes me happy as a counsellor is to meet my clients when they are changing, you see, when I counsel someone and the next time is going down, I feel maybe my counselling did not work, but when I see these people changing and they come looking better . . . it gives me an encouragement, counselling is working in their lives, so when people change from the worst to the better, it gives me encouragement, but I don't want to hear that ah, your client died, so when I spend at least four months when I don't hear that your client died, I feel that I'm doing something" (Interview 2 Feb 2009).

Some of the KCCC counsellors spoke in general terms of seeing clients improving and coming back to life, while others spoke more specifically about rising CD4 counts and the role of counsellors in making it possible for clients to realise the 'miraculous' potentials of ARV treatment. In the AIDS clinic in Maracha Hospital, Joyce mostly expressed frustration and resignation in her limited abilities to counsel clients to change their behaviours, especially in relation to disclosure and reproductive decisions⁸⁵.

The KCCC counsellor Rose most acutely outlined the contradictions of 'informed decisions' in a discussion of clients who failed to make 'positive decisions'. She talked about how it made her happy when clients 'come back to normal life', but then she said; "But when I counsel someone and he does not listen, he does . . . the opposite of what we talked about, I feel

⁸⁵ The interns were mostly frustrated about the limited pay they received.

discouraged”. Later in the interview I took up this statement and asked her: “But sometimes, you talk about something and then the clients they do the opposite?” Rose replied;

“Yes, when it, especially when they become alright, they gain the strength, when it comes to the terms of the, their relationships . . . especially in discordant couples. You tell them the dangers of having unprotected sex . . . the one who is negative may turn positive, and in a few months, you see the wife pregnant [laughing] then you feel discouraged. . . you talk about dangers of smoking and taking alcohol, the client will tell you, counsellor, I have left all of those, ‘aha I’m going to give up smoking, I’m going to give up drinking’, but when he gains strength you meet him when he is totally drunk, he’s smelling, smelling cigarettes, and you feel, you feel unhappy, I feel that he may go back to the way he was” (Interview 27 Jan 2009).

Rose’s frustrations outlines the schism the counsellors are faced with; they feel they have to ‘responsibilise’ the clients to behave in specific life-protecting ways, and yet they do not always succeed. This schism plays out in relation to a number of different social and institutional dynamics in KCCC and Maracha Hospital. In the following section, I briefly outline some of these dynamics by discussing some key the challenges to practising counselling in the two clinics.

Counselling in practice

One of the central ethical principles of counselling is confidentiality (Bond 1995). The need to secure confidentiality is closely connected to the introspective focus of counselling. Getting clients to open up about their life requires an intimate space and that the client trusts that the counsellor will not reveal their inner most feelings to others. The extent to which the counsellors in KCCC valued confidentiality and intimacy was reflected not only in some reluctance to my presence as a researcher in counselling sessions (see chapter 3), but also in their dissatisfaction with the spatial arrangements of counselling. At the beginning of sessions the counsellors would often draw an imaginary line at the open entrance to the booth and say: ‘what we discuss remains here’. Yet the booths were not quite as private as the counsellors would have liked and their placement downstairs was also inconvenient. Sometimes when a client had been referred to the office on the first floor, they found it inconvenient to go downstairs again. This was the reason some of them gave for sometimes having sessions in the office (while other counsellors could be present). It was especially the different types of on-going counselling sessions, which could be conducted in the office or in a corner in the boardroom.

In the AIDS clinic in Maracha Hospital, Joyce did not problematise confidentiality issues. In fact, she never promised the clients confidentiality, and she handled the sessions with the door open so the

other clients waiting on the benches outside could possibly hear what was going on. In informal conversations the interns problematised the fact that they had to provide pre-test counselling as group sessions, because they were so few. Joyce argued that group counselling “doesn’t help much because each person comes with his or her own problem”. But she said that for pre-test counselling group sessions could be ok as a means to ‘give the information’ and then in the individual post-test session, “now you go into details and get the reason why the patient came, so you help him or her to get out that problem” (Interview 12 May 2009).

Apart from challenges to achieving privacy, a range of other dynamics was also at play in counselling. For one, the majority of the counselling provided in the two clinics is mandatory; the counselling in connection with testing and most on-going counselling is not something that clients voluntarily seek out, but comes as requirements for doing an HIV test or as a requirement for clients receiving ARV treatment (in KCCC, such as the mandatory ART enrolment session and the regular ‘check-list’ sessions, and in the Maracha clinic Joyce’s counselling/consultations). So despite the emphasis in non-directive counselling methodology on helping clients to overcome a problem, the clients do not necessarily come to these sessions with problems they want to discuss with a counsellor. Secondly, what clients sometimes did was to ask the counsellors for advice and their requests were not always resisted.

The introspective technique also failed at times. Clients did not necessarily disclose their inner most thoughts and considerations in counselling. When I asked Damian what he had learnt while being a counsellor, he said: “adults are not honest in most cases, sometimes they tell lies . . . someone say I’m not married, but as you journey with a person, of course I have visiting husband, you know that kind of thing” (Interview 19 Jan 2009). Joyce similarly complained that clients were not honest especially about their sexual conduct and reproductive wishes, but also in general about their reasons for missing appointments.

Faced with these practical and social challenges, there were doubts and frustrations over whether non-directive counselling could enable clients to make ‘the right’ informed decisions on how to live with HIV/AIDS. Below, I will turn to the notion of Positive Living to further explore such dilemmas in the counselling practices in the two clinics.

Living positively with HIV/AIDS

In order to situate the contradictions around Positive Living experienced in KCCC and the AIDS clinic in Maracha Hospital, I briefly return to the global level again. Positive Living is another central practice disseminated

within the global assemblage around HIV/AIDS. The concept was initially developed in the US in the early 1980s among people living with HIV/AIDS, but today it is a globally circulated concept, which is used in diverse settings⁸⁶.

In this section I explore the double character of Positive Living as on the one hand a counter-discourse to the association of AIDS with imminent death and on the other hand as rules of conduct for ‘clients’; pointing to how techniques of positive living are being increasingly instrumentalised in the context of the ARV treatment scale-up. I begin this section with the context in which Positive Living initially emerged in the US and how the term developed in Uganda, and then I discuss how ideas and practices of Positive Living were discussed and promoted in KCCC and the AIDS clinic in Maracha Hospital.

Positive Living: positive attitudes and positive lifestyle

The idea of Positive Living was initially developed among the first AIDS activists in the US, who were predominately homosexual men (Siplon 2010). According to Dilger, the idea of Positive Living was linked to ways that gay and black activist groups in the US had begun to use the term living positively in the 1970s, e.g. *Positively gay* and *Positively black*. With these terms the groups were trying to dissolve stereotypes by creating a “‘positively shaped’ collective and individual identity on the basis of individualistic-psychological theories” (Dilger 2001: 76). In a similar way, the first groups of HIV positive people in the US, and other western countries, were fighting a ‘struggle for rhetorical ownership’, trying to invert the negative stereotypical representations of them as ‘AIDS victims’ (Whittaker 1992: 386-387). In 1983, AIDS activists formulated the Denver Principles in which the terms ‘victim’ and ‘AIDS patient’ were rejected for their connotations of defeat and helplessness (Seckinelgin 2002: 117). To date, the notion that people living with HIV/AIDS must not be called ‘AIDS patients’ is followed in most contexts around the globe. In connection with the centrality of counselling, they are often called ‘clients’ instead.

The term ‘living positively with HIV/AIDS’ involves an interesting play of words, which reflects how it is envisaged as a *technology of the self*. With the term Positive Living the association between HIV and imminent death is challenged. The life-destructing connotations of being diagnosed HIV positive are inverted, so instead of referring to a deadly virus, ‘positive’ now refers to the positive attitude and the positive steps one can take to prolong life after testing HIV positive. A central idea is that a positive

⁸⁶ See e.g. Africa Regional Sexuality Resource Centre (2006); Body Positive North West (2010); Grundwald (2006); O'Shaughnessy (n.d.).

attitude is key to one's physical and mental well-being. "It's our attitudes that keep us alive – more so than the drug" said Australian AIDS activist Reg Carnell in 1988 (Whittaker 1992: 389). Positive Living is thus a way of working upon one's self in order to prolong life; first to reconcile with the continued life possibilities after testing HIV positive and then to accept that a certain kind of self-government is required to realise these life possibilities. The fact that Positive Living is often discussed as an empowering practice, is connected to the fact that prior to the advent of ARV treatment, working upon 'the self' constituted one of the only ways in which people living with HIV/AIDS could try to affect the course of the disease (cf. Levy & Storeng 2007; Nguyen 2009b).

In Uganda, it was The AIDS Support Organisation (TASO) that initially made the term Positive Living known and popular. TASO was started on the initiative of Noerine Kaleeba, who was the principal of the School of Physiotherapy at Mulago hospital in 1986, when her husband Christopher was diagnosed with AIDS in the UK where he had been studying (Ssebanja 2007: 5). After the couple had returned to Kampala, Noerine started to bring together a group of infected persons who visited each other in their homes, exchanged information on the disease, prayed together and supported each other (Hampton 1992: 2-4). Initially, the group mainly drew on the Kaleeba couple's experiences from the UK. In Hampton (1992: 4), Noerine mentions the caring attitude of the nurses and doctors, and the 'buddy' system of counselling in the Terrence Higgins Trust⁸⁷ as their inspiration.

In various booklets and reports about TASO, their Positive Living 'philosophy' is presented as a number of principles for everyday conduct that people living with HIV/AIDS are encouraged to follow. These principles include both having a positive attitude and a healthy lifestyle (e.g. Hampton 1992: 2). The booklets also include concerns with avoiding connotations of imminent death and victimhood, in accordance with the Denver Principles. In Hampton 1992, it says that in TASO people with HIV/AIDS are called 'clients' never 'AIDS victims' or 'AIDS sufferers', and only 'patient' if a client is admitted in a hospital (Ibid. 5).

The practical steps to live positively with HIV/AIDS presented in these booklets are not merely suggestions for how to prolong life, but also have a character of responsibilities. In a joint TASO and WHO publication, TASO's Positive Living philosophy is defined as a set of rights and responsibilities of people affected by HIV/AIDS and their communities (TASO/WHO 1995: 2). It is defined as the responsibility of people living

⁸⁷ The Terrence Higgins Trust, established in 1982, was the first charity to address HIV/AIDS in the UK (Seckinelgin 2005: 116).

with HIV/AIDS “to cultivate self-esteem, hope, respect for life and protection of their community, care for self, care and support for dependants” (Ibid. 3). The appropriate care of the self for people living with HIV/AIDS is elaborated in a list of responsibilities. This list is also what appears on TASO’s website today as the definition of Positive Living⁸⁸:

“Those who come to TASO are encouraged to live positively with HIV/AIDS. In practical terms, clients are encouraged to:

- *accept their diagnosis*
- *seek counselling*
- *seek prompt medical care*
- *maintain a balanced diet*
- *practice safer sex*
- *have adequate sleep and exercise*
- *continue to earn an income*
- *continue with normal social activities*
- *plan for the families and dependants*
- *avoid harmful habits such as drinking alcohol and smoking”*

(TASO/WHO 1995: 4).

In its wide-ranging scope, this elaborate ethics of self-care has parallels to how KCCC informants defined holistic care. But whereas holistic care was defined as helping people living with HIV/AIDS with their multi-faceted needs, Positive Living implies an individual responsibility to work on the self in multi-faceted ways. Whether Positive Living also encompasses rights (as implied above) for example to access social and economic assistance, which can help you to live up to these responsibilities, is the theme of chapter 7.

In the 1990s, the notion of Positive Living seems primarily to have been an urban phenomenon (Whyte 1997: 216), but with the spread of AIDS support and treatment services across Uganda, the notion has become widespread. Today Positive Living is a widely used concept. *Living positively* has even become a standard way of simply referring to a person living with HIV/AIDS, not necessarily implying that the person is trying to follow this or that definition of Positive Living.

Positive Living in KCCC and Maracha Hospital AIDS clinic

In KCCC and Maracha Hospital, the counsellors to varying degrees talked about the double character of Positive Living, as both a matter of clients having a positive attitude towards being HIV positive, and as specific recommendations of conduct for clients. In the Maracha clinic, when asked about Positive Living, the counsellors mostly listed Positive Living

⁸⁸ See <http://www.tasouganda.org/>

recommendations. Only the intern counsellor Patrick mentioned how people living with HIV/AIDS had to be encouraged not to fear dying:

“if you're positive . . . if you are aware, you know where to go next . . . support from your community leaders or from your guardian to look after you or to take you to hospital, so wherever you go, they can assist you, and taking the drugs can also prolong your life, you may stay long even, it will also make you healthy, it does not mean you are sick you are going to die very soon. When your positive it doesn't mean you are dying very soon . . . even negative people die, why fear? You go open, so that your life will be long“ (Interview 28 Apr 2009).

Patrick's statement reflects how the two sides of Positive Living can be connected: if you become aware of and accept your status, you can access assistance to help you prolong your life. In KCCC, the counsellors also emphasised this point of encouraging clients to not look at being HIV positive as a death sentence. Charles for example said:

“but we've seen people living for 20 years, how have they lived? Yeah it is because they tend to, not always to think about being positive . . . their mind tends to say that yes I'm positive, I know I'm positive, but I can still do something A, B, C, D that can keep me continuing living” (Interview 12 Feb 2009).

When I asked the KCCC counsellors what issues they needed to address to ensure that clients live positively, the counsellors provided long lists of life-prolonging recommendations. Daniel for example said in “positive living we normally look at a number of issues”. He mentioned nutrition (a balanced diet), personal hygiene, treating infections early, taking medicine in the right dosages at the right time, socialising, empowerment in terms of income generation, disclosure, and finally ‘not to forget’ preventive measures (Interview 3 Feb 2009).

What is central to notice is how Positive Living today has been incorporated into counsellors and community worker's attempts to govern the conduct of people living with HIV/AIDS. An example from the HBC programme coordinated by Ediofe Health Centre is instructive. When I asked the community counsellor Josephine what she normally discusses with clients when she goes on home visits, she replied:

“Ok, now the first thing we discuss with the client is, you talk about positive living, how to live with this virus positively, that is how is the client taking the drugs is he taking the drugs correctly or badly . . . also secondly, you also talk about hygiene . . . you also talk about the food type that person is supposed to eat . . . (Interview 17 May 2009).

It is my argument that over the past two decades Positive Living has been increasingly instrumentalised as a method for governing the self-government of people living with HIV/AIDS (as least in African countries). Prior to the scale-up of ARV treatment in Sub-Saharan Africa, there was a bio-political potential in promoting Positive Living among

people living with HIV/AIDS to mitigate the effects of AIDS, to encourage others to be tested and to ensure that they protected others from being infected. But in the context of ARV treatment, the bio-political importance of Positive Living is intensified: to ‘save lives with ARV treatment’ it has become ever more central to activate a desire in each individual to fight to prolong life, now by following treatment requirements. Activating such a desire can be a way to resolve the question of how to make sure clients take responsibility for making ‘positive decisions’. With this instrumentalisation the dual character of Positive Living tends to shift in balance, so that ‘the positive attitude that keeps us alive’ more becomes a matter of getting clients to ‘accept their diagnosis’ so that they will be encouraged to follow the recommended life-prolonging steps.

Techniques of Positive Living: accepting your new social and biological truth

It was especially in KCCC that the counsellors discussed specific techniques of how to encourage clients to accept the new life potential after testing HIV positive. In this respect, testing HIV positive can be seen as a new social and biological truth that the person testing positive has to reconcile with, so that he or she can start a new life conducting him or herself according to this truth. Rose explained:

“When a person is tested positive, HIV positive, first of all has to be empowered to accept . . . he’s HIV positive and he can live, he can live longer despite being HIV positive, and if he has accepted his status, it makes him live longer and it makes him protect himself and others that he’s living with, even it makes him accept the medication that is given to him and other social services that are giving to them, but if he fails to accept himself, all, all that is given to him he sees it as, as nothing, as useless, and he can, he neglect himself and everybody, those are the people you find committing suicide or just neglecting medicine, thinking that even if they took the medicine the end result of it is death”(Focus group discussion 16 June 2008).

According to Rose empowering a client to accept that he can still live after testing HIV positive, is a necessary first step to ensure that clients take on responsibility to live longer, to protect others, to accept medication and other social services given to him. In other words, accepting your new social and biological truth is a prerequisite for responsible self-government. Similarly, Daniel explained how clients need supportive counselling to accept the situation in order to ‘plan ahead’ and even to be able to take treatment:

“this person needs a lot of supportive counselling, . . . to help this individual move from that element of denial to accepting the situation and then plan ahead, because as long as the individual doesn’t accept the situation, he or she is in, then you can’t think of treatment, because will ask you, why me? What have I done to God? . . . you keep giving support so that, this individual tries to cope with the

new challenge and tries to accept, because not until you have accepted, you cannot even go for treatment” (Interview 3 Feb 2009).

As illustrated by Nguyen (2009b) and Jørgensen (2006), Positive Living can be framed as a conversion-like process: as a matter of “greater enlightenment and the adoption of more, responsible moral life” (Nguyen 2009b: 372). Jørgensen demonstrate how the counsellors in Reach Out stressed acceptance of HIV positivity as the precondition for the new purer life of *living positively* (2006). Some of the KCCC counsellors also spoke about encouraging clients to accept their status in spiritual and Christian terms. This was especially Damian, Anthony and Charles who were originally trained as pastoral workers. But rather than a conversion to a new life, their approach seemed more focused on the ‘journeying’ described earlier. Anthony explained that clients need to reconcile with themselves, with others and with God before they can live positively:

“the moment they know they have HIV/AIDS, there is a lot of questions which run out of their minds, first of all, why me? Why is this happening to me? . . . what did I do for God to punish me? Some patients have an attitude that when they get HIV, it is God punishing them, there is a lot of guilt amongst them, there is a lot of un-forgiveness amongst them. . . we want to help these people, to have that reconciliation . . . first of all to the self, because some people deny themselves, they pity themselves, they say, I did a lot of wrong things, that I should have this punishment, so our approach is to . . . people suffering from HIV/AIDS to forgive themselves, to forgive others and forgive God” (Focus group discussion 16 June 2009).

Anthony went on to further explain that overcoming blame of oneself and blame of God is central to accepting the new kind of life that is possible after testing positive, because if a client does not reconcile him or herself with God, the client may see life as useless:

“... if there is no that relationship, the reconciliation between the self and God, then it is a problem. That’s where you find some people think of committing suicide, their life become useless. But when I go there as a pastoral counsellor and I say “you see, God still loves you even when you have HIV, God is very near to you” (Focus group discussion 16 June 2009).

In its emphasis on reaffirming the person’s worth by confirming the presence and love of God, this approach is similar to how the pastoral workers talked about ‘journeying’ and the sacrament of presence. Charles further explained the rationale that clients need to appreciate that God still loves them for them to love themselves; “God loves us and we need to care about our lives and God also cares for us” (Interview 12 Feb 2009). With the pastoral approach, the counsellors link ‘accepting your status’ to realising God’s eternal love and places the individual client’s responsibility to live positively as steps towards ‘healing the broken creation’.

To the extent that these pastoral approaches are incorporated into counselling sessions it reflects how Christian pastoral practices can be incorporated into psychological techniques of self-transformation, as also identified by Burchardt in South Africa (2009: 350-1). However, Anthony, Charles and Damian were in fact in agreement that pastoral work in KCCC had been neglected for some time. In early 2009 they had begun to discuss with the management about how to revive it. From the counselling sessions I observed it seemed that indeed a pastoral approach was not that central, although it was part of a repertoire of techniques counsellors could use in certain situations. The counsellor/pastoral workers' experience of neglect of pastoral care reflects one of the ways in which holistic care have had to be negotiated with bio-political ambitions.

In general there was a disconnect between how much the counsellors talked about techniques of empowering clients to 'reconcile with their status' in interviews and focus group discussions and the fact that these techniques did not appear as central in the sessions I observed. Out of the 34 sessions I observed, there were only three sessions in which the counsellors used the kind of techniques described above. In some of the instances where a client tested positive, the post-test session had a decisively bureaucratic focus, the counsellor focusing on registering the client's details and making an appointment for a CD4 cell count. Of course the nature of the post-test session depended on the client's reaction to the positive results. In one session where a young woman reacted with shock to her positive test result, the counsellor used techniques like those described above.

The counsellor handling this session was Olga Nansamba, a young Catholic woman who is openly living with HIV/AIDS. My assistant Norah and I were present during both the pre-test and post-test counselling. The client was a young woman, whom I call Nadine. Because of the sensitivity of the situation, I did refrain from my usual practices of taking notes while the post-test session was going on. The notes below were written up afterwards.

Nadine was a young smartly, dressed woman, who quickly announced that she was a Born-Again Christian. When Olga in the pre-test session asked Nadine, which results she expected from the test, she replied that she expected the results to be negative.

However, the test results were positive. When Olga gave her the results in the post-test session, Nadine first looked as though she didn't believe it. After some seconds, she raised up one hand, then both hands. Then she completely collapsed on the chair and fell down. Olga grabbed her, and then she and Norah held her and conformed her for quite some time. When Nadine seemed to be over the worst shock, their conversation continued.

Nadine seemed to be most concerned about what the test result meant for her relationship with her boyfriend – also a Born-Again Christian. One of the first

things she said was: *Now what will I say to my boyfriend? I've only had sexual relations with one person. He went to South Africa.*

Later she explained that she had been dating her boyfriend for two years and that he had *never said anything that he wanted to have sex*. She explained that they were planning to get married and that she had already taking him to her parents in December, and the Introduction⁸⁹ had been arranged.

During the session, Olga brought in her own experiences of living with HIV. She shared how she had also reacted in shock when she was first told she was HIV positive in 2001, when she was pregnant with her last born. But Olga explained that many of the people, who had laughed at her for being HIV positive, had since died.

She tried to comfort Nadine by saying; *God will make a way for you. The God who created you, He knew all this. Why do people sing songs praising God, it is because of the problems they go through.* She encouraged Nadine to try to have a positive approach to the situation, she said: *The biggest problem, which aggravates this disease, is worry. Dedicate your life to God. Live with people who can make you happy.*

Olga also assured Nadine that she had many years left to live and with the medicine she would be able to live long; *you'll get medicine and you'll be well. We have clients who knew their status in 1987, over 20 years ago. Now they don't even have any problems, because there is treatment.* Nadine objected a bit *'the problem is I don't have money. Doctors need money, and you need to feed well'*.

Olga explained that 'feeding well' did not have to be expensive and that buying some pineapple for 100 shillings could be better than eating meat or 'frying' (i.e. making a stew). She also assured Nadine that in the clinic she only had to pay a fee of 1,500 shillings and if she did not have any money, they would still treat her *'They can't leave you. So you shouldn't be discouraged'*.

At the end of the session, Olga concluded by assuring her *'I will always be there for you'* and with urging Nadine to view the situation as part of God's plan for her; *'there is a reason why he has brought it. He will make you go through this situation'*. Olga then asked my assistant Norah to close with a prayer.

After lunch, in the counselling office, Olga talked with the other counsellors about how moving and challenging the session with Nadine had been, and said: *I had to use so many methods, I had to give my testimony, and I had to go pastoral* (Fieldnotes 7 Jan 2009).

By emphasising how being HIV positive does not mean that life is over, Olga tried to support Nadine come to terms with the shocking news of testing HIV positive. Olga used three ways of exemplifying Nadine's continued life potential after testing positive, one was to use her own and other 's experience of living for several years with HIV. The other was a

⁸⁹ The introduction ceremony is the customary ceremony of modern wedding ceremonies among e.g. the Baganda and the Basoga. There are held prior to the wedding ceremony. During the introduction, the groom pays bridewealth to the bride's kin members.

commonly used method of referring to the uncertainty of all life (those who are negative also die). The third point was the possibility of prolonged life, which taking ARV treatment holds. In addition, Olga also made use of a pastoral approach, encouraging Nadine to rely on and turn to ‘her God’, and accept the situation as God’s plan for her. In doing so Olga made specific references to Pentecostal forms of Christianity to link to Nadine’s Born-Again identity⁹⁰. Finally Olga encouraged Nadine to have a positive attitude, in a way which connected ‘worrying’ to a more rapid progression of HIV (this linkage will be discussed further below). In chapter 9 I will return to this session to discuss Nadine’s situation in more detail.

Testing positive in Maracha Hospital’s AIDS clinic

In Maracha Hospital, Joyce did not employ or talk about such techniques to make clients reconcile with their new social and biological truth, which were occasionally used by the counsellors in KCCC. A session with a young woman who had just tested positive will reflect the difference between Joyce’s counselling-consultations and how counselling for Positive Living at times were approached in KCCC.

When the woman entered the consultation room she did not seem to be in any state of chock over testing positive. Joyce began the session what a number of practical, bureaucratic issues; she registered the clients in the Ministry of Health ART register, and informed her that she had to buy an exercise book to use as her file. Only then did she ask the woman: ‘When you were told that today you are positive, what decision did you make?’ The woman replied: ‘I just chose, if I’m now positive, I should just take the drugs’. Joyce then asked her whether she had a husband and whether she had children, and Joyce encouraged her to bring her children for testing. They then discussed whether the woman had anyone who could help her collect drugs in case she would not able to come to the clinic, and the woman replied that her brother could do that. Joyce asked to her coughing history and since she had coughed for a long time, Joyce referred her to go to the clinical officer to have her sputum tested for TB. Joyce then concluded the session with this statement:

Joyce: . . . Today I’m giving you this drug, once you start this drug, you should not take alcohol and not smoke. You should remove that tendency that ‘I’ve got this virus from someone, let me also give it’, once you do that, you will get re-infection. I’m giving you this septrin, it will help you prevent minor illnesses like cough, malaria, it also prevents the virus of reproducing many. It also increases your immune system to fight against diseases. Drugs also go with food, you should keep eating food as you take this drug. I advise you to be free, don’t think that with this virus you will die soon, if you follow the instructions I’m telling you,

⁹⁰ For example she referred to the song ‘I surrender to you my Lord’ and she asked my assistant whom she knew to be Born-Again to conduct a closing prayer.

it will increase your number of years, it will enable you to cater for your children
(Fieldnotes 17 Mar 2009).

Joyce's rather long concluding statement can be read as a concentrated and generalised instruction on Positive Living. Noticeable these are 'instructions' that the client should 'follow' to prolong her life, not attempts at making her come to terms with her new life situation. Joyce did ask her 'what decision she had come to', and advised her to 'be free', but in contrary to the session with Olga and Nadine there was very limited emphasis on and room for an individualised exploration of her feelings of testing HIV positive. One similarity between the two sessions, however, is the way the counsellors encouraged the client to have a positive attitude and not fear dying because that would speed up the progression of HIV. This point reflects one of the way in which Positive Living is instrumentalised for the sake of treatment efficacy.

Self-responsible clients – core concerns

In this section I explore further how the contradictions of counselling and Positive Living in KCCC and Maracha Hospital play out in practice, by considering some of the counsellors' core concerns and core techniques of promoting responsible self-government among their clients. I discuss three concerns and techniques: first the use of CD4 counts as a marker and technique for self-government, the emphasis on proper nutrition and finally the question of client's sexual responsibility.

CD4 counts as marker and technique for self-government

With the scale-up of ARV treatment, diagnostic technologies such as CD4 count and viral load equipment has spread across Uganda. However, as shown by Meinert et al. (2009), these diagnostic technologies are distributed unevenly in Uganda's ART provision landscape. In KCCC, the CD4 count embody the progress client is making in 'positive living' (as in following life-prolonging steps), and the CD4 count is also actively used a method to encourage responsible self-government among clients. In the AIDS clinic in Maracha Hospital there is no CD4 machine, but here the weighing scale is used in its place.

The CD 4 cell count indicates the level of immune deficiency caused by HIV⁹¹ and is globally the widely accepted diagnostic technology for monitoring the progression of HIV. In KCCC, clients are introduced to the concept of 'CD4' during post-test counselling. When clients test positive,

⁹¹ The absolute CD4 cell count measures the number of CD4 T-cells in each millimetre of blood. For a healthy, HIV negative adult the normal range is between 450 and 1600 cells/m³ (aidsmap 2011).

the counsellors make an appointment to do a CD4 count to determine whether the client is eligible to start ARV treatment. After the first CD4 count, clients are supposed to come back every 6 months to do a CD4 count, and in this way monitor the progression of HIV in their body⁹². Once they begin ARV treatment, the regular CD4 count is meant to monitor the efficacy of treatment. In counselling sessions, the clients are educated about what they can do in their daily lives to increase the number of CD4 cells in their body, and which things they should avoid, because they may decrease their CD4 levels. In this way, the daily life-prolonging recommendations of Positive Living are reconfigured as methods to optimise ones CD4 count. This means that now the degree of one's adherence to Positive Living can be measured with biomedical technology.

When the CD4 count indicates that the client is eligible to start ARV treatment, the client first has a session with his or her counsellor discussing the implications and requirements of the treatment. The client is then referred to Jagwe's ART enrolment sessions. In these sessions, Jagwe takes a group of three to four clients through a comprehensive ART education exercise. Here, he continues the education on CD4 cells, their meaning and how as a client you can actively increase them. In Luganda, Jagwe calls the CD4 cells *aba silikale* (our soldiers)⁹³. During the education, Jagwe uses the term 'enemies of the CD4', which conveys an image of all 'the bad things', clients are supposed to avoid. For example:

Jagwe: *This CD4 have got 5 major enemies, who do you think?*

Client 1: *Being promiscuous*

Client 2: *Over-having sex. This thing overworks you*

Client 1: *Then worries . .*

Client 2: *Even poor feeding*

Jagwe: *All these things disturb the CD4. There is 1. poor feeding, 2. worry, 3 overworking your body, 4. Sickness, 5. Delivering – delivery disturbs your body*

Client 1: *Thoughts...*

Jagwe: *There's something we missed; there's HIV. I talked about it in the beginning. You may settle well, but the HIV is eating your cells. We are here to fight the HIV, because we don't have any options* (Fieldnotes 14 Jan 2009).

As this example illustrates, Jagwe is trying to make the clients responsible for the fight against HIV in their own body, by educating them on what

⁹² However it seems that this was not always systematically followed.

⁹³ Also using war metaphors, Olga often talked about CD4 cells as the Ugandan Army (UPDF), and the HIV virus as Kony, the leader of the Lord's Resistance Army. Another common word used for the CD4 cells in Uganda is the Swahili word *askari*, meaning guard (Meinert et. al. 2009: 197).

they can do to increase 'the soldiers' in their blood. Educating clients on the enemies of CD4, and doing regular CD4 counts, is thus used as a way to encourage clients to prolong life and achieve treatment success by taking responsibility for managing their CD4s well. Notably this technique turns the importance of having a positive attitude into a recommendation 'not to worry', because it harms the CD4 levels. When Meinert et. al. (2009) points to how people living with HIV/AIDS in Uganda appropriate diagnostic technologies like CD4 counts to reflect upon their lives, bodies and relationships with others, it should be noted how using techniques like educating clients on the enemies of the CD4, helps to constitute the CD4 counts as a marker of how well they are 'performing' as good clients. Kalofonos similarly found in central Mozambique that the CD4 count was used a kind of moral barometer of proper lifestyle by providers, patients and activists (Kalofonos 2008: 135).

In the AIDS clinic in Maracha Hospital where CD4 counts are not available more simple measures are used for monitoring the medical state of a client: weight, physical appearance and symptoms/diagnosis of opportunistic infections. Particularly the client's weight is used in similar ways to the how the CD4 count is used in KCCC to attempt to make clients take responsibility to prolong their life. After the client is weighed at the start of the consultation, Joyce usually ask the client 'why is your weight dropping' or 'why is it not increasing?' At the same time, Joyce routinely educates the clients on the importance of eating well when being 'on treatment'. Consequently, gaining weight becomes in similar ways to the CD4 counts a barometer for proper conduct as a client.

Eating well

An important aspect of encouraging responsible self-government in both KCCC and Maracha Hospital concerns counselling clients on the importance of eating well, especially when taking ARV treatment. There is globally, and especially in the African countries, a great emphasis on nutrition in treatment and care programmes, because of the way HIV infection and malnutrition may be mutually exacerbating (Anabwani & Navario 2005, Haddad & Gillespie 2001). Additionally, for ARV treatment it is widely assumed that nutrition is essential for adherence and a good therapeutic outcome (UNAIDS/WFP/WHO 2008). If clients begin ARV treatment once they are in advanced stages of AIDS, they will often have experienced a loss of appetite caused by prolonged inflammatory and immune responses (Anabwani and Navario 2005), which means that the reconstitution of their immune system brought about by the treatment may lead to a dramatic increase in appetite (see e.g. Kalofonos 2008).

The differences between KCCC and Maracha Hospital's AIDS clinic in terms of technological sophistication is also reflected in the techniques used to educate clients on how precisely they are to 'eat well'. The differences between an urban and a rural context are also significant here. As my research in Maracha Hospital was conducted during a time of pronounced food shortages during 'the hunger season'⁹⁴, this reflected the kind of techniques used when educating clients to eat well.

In Maracha Hospital, Joyce would generally remind clients that 'the drugs go with food'. However, when Joyce enquired to clients' lack of weight-gain, the client often replied that 'there is no food'. Therefore Joyce and the other counsellors generally emphasised to clients that they should try to 'just eating something'. For example, to a young woman whose weight had reduced from 51 to 50 kg, because as she said 'the food is not enough', Joyce said: 'I advise you to get any possible means to eat something when you take this drug. It will work well with food. You can make porridge of millet, it is good' (Fieldnotes 20 Mar 2009). The counsellors also stressed ways of getting something to eat, which is not part of what primarily counts as 'food' in the area (food usually implies eating some kind of staple food, most often millet or cassava porridge). During home visits in Otravu, we visited a couple who had a big compound with many fruit trees and Joyce said to the woman: 'I'm happy I can see the fruits here that I told you are good for your body. These fruits are good to take drugs with' (Fieldnotes 29 Apr 2009).

In KCCC, the counsellors placed great emphasis on educating clients to have a 'balanced diet' and on connecting the need for a balanced diet with managing ones CD4 levels. The balanced diet was especially in focus in the ART enrolment sessions. To educate clients on the concept, Jagwe distinguished between three different types of food, explaining how each type of food has a different function in the body. For example:

Jagwe: *What are the enemies of CD4?*

Female client: *Poor feeding, but what if I don't have the money to buy?*

Jagwe: *What could good feeding be?*

Female client: *Fish, meat etc. but if I don't have money it will make me depressed when you can't get the food you're supposed to.*

Jagwe: *Good feeding is not only about these good, good meals. Let's look at the different types of food. There is energy-giving food, body building food and food that protects our bodies. What are the energy-giving foods?*

Female client: *Sweet potatoes, pumpkin, cassava, posho*

⁹⁴ 'The hunger season' is the time when people have begun to cultivate the land for the second harvest of the year, and food supplies begin to run out, before the new crops can be harvested.

Jagwe: *There is also irish⁹⁵, rice, anything from the ground. Then there is body building foods like beans, fish, cow peas, soya, milk, egg. And the food that protect our bodies are greens and fruits. What you get is what you eat. That one can cost just 100 shillings. Not for your whole family, for you. It's not about just eating to fill your stomach.*

As the virus is breaking down your body, you also build it up. It's not about this rich thing, if you have money for beef, liver, you buy it, but if you only have money for beans and dry fish, you get that. It's just this common food we eat, so don't fear (Fieldnotes 17 Dec 2008).

What Jagwe explains to two clients is that eating well in the context of taking ARV treatment, is about building up the CD4s that the virus is 'eating'. But eating well is not about 'these good, good meals', but about eating food from all the three categories of food: carbohydrates, proteins and foods rich in vitamins and minerals. Generally in Uganda, eating well is associated with affluence, for example with having enough money to eat meat regularly and to eat a variety of foods. Therefore the method that Jagwe and the other KCCC counsellors use is to inform clients about inexpensive ways of having a balanced diet. The importance of stressing to clients that having a balanced diet is not only for rich people is reflected by the concern this female client expresses over not having enough money for 'the right food'. This kind of dynamic was also reflected in the session with Olga and Nadine. A possible fear over not having enough to eat to take the drugs is also connected to how clients are regularly informed that it is not good to take ARV medicine on an empty stomach.

Attempting to render clients responsible for 'eating well', also involves questions about the clients' income and livelihood, and about the extent to which it is possible and acceptable for a client to eat 'special things' that no one else in the household gets. These dilemmas are further discussed in the following chapters.

Sexual responsibility

In discussions of Positive Living the emphasis is usually placed on the practice's potential in mitigating the impact of the AIDS epidemic through prolonging the lives of people living with HIV/AIDS (consider e.g. Levy & Storeng 2007; Grunwald 2006; Dilger 2001). This emphasis misses the point that Positive Living can also serve another bio-political objective: to help reduce HIV prevalence. As reflected by TASO's definition and Daniel's listing of Positive Living issues, living positively also involves an ethical requirement to protect others from infection.

⁹⁵ Irish is short for Irish potatoes, which is what potatoes introduced from Europe are called to distinguish them from local sweet potatoes.

One of the ways in which the counsellors in KCCC connected Positive Living and sexual responsibility revolved around the fears of people living with HIV/AIDS deliberately or recklessly spreading the virus. During one of my very first visits to KCCC in April 2008, the counsellor Esther and the community worker Joy explained to me that both counselling and home visiting had a significant pastoral component. Referring to the Luganda saying *nange, samuja ku mutti* (also me, I didn't get it from a tree), they talked about how people living with HIV/AIDS might be so resentful or bitter that they became determined to pass on the virus to others. Esther and Joy explained that when people test HIV positive, they tend to think that God has forgotten them, and therefore, the purpose with pastoral care is to assure them that being HIV positive is not a punishment from God: 'The spiritual component prevents people going around trying to spread the virus' Joy said (Fieldnotes 2 Apr 2008).

Charles also explained how some clients as a consequence of getting counselling and support now took active part in 'preventing themselves to infect others'. He claimed that the clients would make statements like:

"ah, if I have it, I don't desire to spread it to others you know once I do it, I'm committing a sin before God . . . I've reconciled with my God and I have to live with it, so let me protect others, so that the younger generation that is coming would not also enter into the same" (Focus group discussion 16 June 2008).

In this perspective, accepting your HIV positive status as part of God's plan, and accepting to live positively is about *positively* participating in protecting others from infection. This reflects how faith-based HIV counselling may have a focus on creating ethical selves as argued by Burchardt (2009: 351). At the same time, however, the counsellors' discussion also establish a link between the purpose of reaching out to people living with HIV/AIDS in compassion with that of protecting yourself from their otherwise vengeful tendencies⁹⁶.

'Remain with your virus'

In Uganda, the introduction of ARV treatment appears to have re-actualised concerns with the role the sexual conduct of HIV positive people play in reducing or increasing HIV prevalence (see e.g. Bunnell et al. 2006). Research indicates that well administered ARV medicine can reduce a person's viral load to the point where the person is no longer infectious (e.g. Castilla et al 2005). Yet, in Uganda there are concerns about the

⁹⁶ Such connections were also made in HIV/AIDS prevention programmes, both in KCCC and in the sensitisation project run by Arua diocese. The message that people should show care and compassion to people living with HIV/AIDS was at times driven home with dramatic stories of how hurt and bitter HIV positive people in revenge deliberately had infected others.

possibilities of returning to almost 'normal life' that ARV medicine brings, since this return may involve renewed sexual and procreation desires. Moreover, with ARV medicine people living with HIV/AIDS can live for long without the visible signs of AIDS, and there is in Uganda a growing concern that 'the good looks that come with ARVs' will increase the prevalence of HIV as one news paper article reported (Daily Monitor 19 May 2009). This concern was a frequent topic of discussion in informal conversations with counsellors and other employees in the three organisations.

Additionally, there is the concern with 're-infection'. The risk of re-infection is connected to the fact that HIV mutates so rapidly that if you as HIV positive have unprotected sex with another HIV positive person you may become infected with a different strain of HIV, which could increase the viral load in your body (see e.g. Jost et al. 2002). In the context of ARV treatment, the concern is furthermore that you could infect others with a strain of HIV, which is resistant to the particular drug combination you have taken (e.g. Brenner et al. 2004).

In both KCCC and the AIDS clinic in Maracha Hospital, clients are encouraged to use condoms or abstain from sex primarily with reference to avoiding re-infection. In this way, the counsellors tend to speak to the self-interest of the client in prolonging life and ensuring the efficacy of the ARV medicine rather than instilling an ethical responsibility to protect others. To the young woman who had just tested positive, Joyce said: 'You should remove that tendency that 'I've got this virus from someone, let me also give it', once you do that, you will get re-infection' (Fieldnotes 17 Mar 2009). Joyce told another woman who was taking ARV treatment:

'Once you're taking this drug, you should not take alcohol, smoke and not play sex unnecessary, if it's with condom, it's ok. Once you have started taking this drug, you're advised to use condoms simply because if you have sex you will add viruses to yours, yet you have started taking the drugs to help you reduce the virus' (Fieldnotes 17 Mar 2009).

In the first example, Joyce implies that people living with HIV/AIDS may have a desire to vengefully infect others. She cautions the client that should she attempt to infect others, she will merely make it worse for herself. In the second example she connects avoiding re-infection to achieving a good therapeutic outcome on ARV medicine.

In KCCC the counsellors use similar techniques, especially Jagwe. In his ART enrolment sessions, he uses mottos like 'stay with your virus' or 'remain with your virus' to come across with the point that clients should practice sexual responsibility in order to avoid re-infection of both themselves and their partners. For example he said:

'When you're starting to take this medicine, it will do miracles. The problem is if you start infecting other people. You oppress this virus, and you give it to someone else, this virus is resistant, you will be giving that person a problem. You may think you're giving the virus to someone else, but they're actually giving you another virus, perhaps a resistant one. At least stay with the virus you have' (Fieldnotes 17 Dec 2008).

What is interesting in Jagwe's statement is the way he moves from first emphasising an ethical requirement to protect others; 'you will be giving that person a problem', to ending the argument with speaking to self-interest in protecting yourself and ensuring the efficacy of the treatment.

In other sessions, Jagwe implied that having sex might not be healthy for people living with HIV/AIDS. He placed sex among the activities, which can 'overwork' you. He said for example: 'sex can overwork you. Some people want to do it daily, that one will wear you out' (Fieldnotes 20 Jan 2009). The clients were also quick to participate in such talk by mentioning 'over-having sex' as one of the enemies of the CD4 (see example above). These examples illustrate how the counsellors' attempts to promote sexual responsibility among the clients are informed by common perceptions that the sexual practices of people living with HIV/AIDS are possibly morally suspect.

'In fact they are not supposed to get pregnant'

The national clinical guidelines on ARV treatment emphasises the rights of women receiving ARV treatment to make reproductive choices (Ministry of Health 2005: 25). However, among the counsellors in KCCC and Maracha Hospital, there was considerable doubt about whether it was appropriate for clients to have children. This experience is paralleled in another study from Uganda, which highlighted counsellors' doubts and negotiations around reproductive choices and ARV treatment (Richey 2009a). The doubts can be connected to the illogical practice of on the one hand encouraging clients to abstain or use condoms to avoid re-infection and on the other hand promoting reproductive choice (cf. Richey 2011).

In Maracha Hospital, Joyce was adamant that "in fact they are not supposed to get pregnant, but depends if God gives you to become pregnant there is no problem . . . when it, the times comes for delivery you need to come and deliver in the hospital where you are helped" (Interview 12 May 2009). But Joyce often complained that female clients did become pregnant, and often did so without informing her first; 'most of the people who live positively say they're not having sex, and then I see them getting pregnant' (Fieldnotes 5 Mar 2009), she said during a home visit.

Similarly in KCCC, the counsellors contended that it was difficult to get clients to be open about their reproductive wishes and desires. For

example, Damian claimed that no clients “comes to consult about that, they just present when they are already pregnant, what can I do?” (Interview 19 Jan 2009). These experiences represent some of the ways the introspective techniques failed. These failures may be connected to the way counsellors discussed reproduction with clients. In a check-list session, my assistant noted the following interaction between Damian and a male client:

Damian: *What plans do you have now? Because I saw your wife delivered a baby, how are you going to control that?*

Client: *We are going to discuss with her and see how we control it. The problem is with condoms, we used protection and she became pregnant. In a way I was happy because I was having only girls and now that one she delivered a boy. So it was a blessing in disguise.*

Damian: *But discuss with your wife to see that you stop producing. Is she on ARVs and septrin also?* Client: *Yes* (Assistant notes 4 Feb).

The message that Damian quite clearly gives to this man is that clients are not really supposed to have children; especially if both husband and wife are taking ARV treatment. Apart from the doubts over whether it is appropriate for clients to have children, as Catholic health facilities, KCCC and Maracha Hospital cannot provide the clients with contraceptives.

Condom questions and relationship management

Despite KCCC and Maracha Hospital's status as Catholic health facilities, the counsellors do encourage condom use, as well as other forms of contraception, as part of being a sexually responsible client (though they generally do not provide them). This pragmatic position to condom use stands in contrast to how condom use was usually presented in Catholic HIV prevention seminars.

There was in my experience a stark contrast between the context of HIV prevention and the context of counselling people living with HIV/AIDS. In the Catholic HIV prevention seminars I have observed in KCCC, Arua Diocese and in Reach Out, condoms were most often presented as a morally inferior prevention method, which may protect you from HIV infection but not from the consequences of sinful behaviours, such as 'adultery' and 'fornication' (see e.g. Rasmussen 2007; 2008). In the Kampala setting, the authority of medical science was also sometimes invoked to indicate that condoms were also a medically ineffective HIV prevention method (e.g. that condoms are not 100% effective). The official position of the Catholic Church is that all forms of contraception are morally wrong (McBrien 1994: 982)⁹⁷, because it violates the reproductive

⁹⁷ However there has since the 1960s been heated debates within the Catholic Church on the need to adjust the Church's teaching to 'today's circumstances' (McBrien 1994:

obligations of marriage (e.g. Pontifical Council for Justice and Peace 2004: 132-3; Mahon 2004). In the Catholic organisations I have studied it is thus remarkable how the bio-political ambitions to save lives with ARV treatment is prioritised higher than such central Catholic principles of ‘the good life’.

However, the counsellors often had to position their recommendations of condoms use against the Catholic identity of the organisation, and some of the counsellors also emphasised that condoms are not a 100% effective HIV prevention method. During a pre-test session with a young woman, Jagwe (who is a Protestant) for example said: ‘This organisation is build on a strong foundation of the Catholic Church, but as a counsellor I talk about condoms, because I know it is one of the ways you can protect yourself. But it is good that you know they are not completely safe’ (Fieldnotes 17 Dec 2008). In Maracha Hospital, a male client, whose wife is a client in a government clinic in Koboko, asked Joyce: ‘Do you have condoms here?’, speaking quietly Joyce replied:

Yeah, condoms are here. When condoms are brought there, they are sent to smaller health centres, because this hospital is of Catholic foundation. We normally don't give here, but for your case I can give. Joyce found some Life Guard condoms in the closed closet and gave the client about 10-15 condoms (Fieldnotes 24 April 2009).

In the interviews with the KCCC counsellors both those who are Catholic and the few who are Protestant said that despite KCCC being a Catholic organisation, they encouraged clients to use condoms in order to ‘protect their lives’. Damian, who is a Catholic, said: “Personally, although the Catholic Church doesn't allow to use condoms, but for heaven's sake, for heaven's sake, for someone's life, that's why I discuss the issue of condom” (Interview 19 Jan 2009).

Importantly, the questions around a client’s sexual responsibility and use of condoms concern not only the individual client but also his or her sexual partner(s). Therefore, the counsellors are also involved in how clients manage their sexual relationships, and they try to encourage and find ways to get clients to come for testing and counselling as ‘couples’⁹⁸.

988). There are groups of Catholic laity and clergy who actively oppose the official policy, such as Catholics for Choice. The Pope’s most recent statement on condom use may also indicate that for health protection reasons the Catholic Church can accept some level of pragmatism, see <http://www.bbc.co.uk/news/world-europe-11804798> (last accessed 21 Nov 2010).

⁹⁸ The notion of ‘couple testing’ was widely used in both KCCC and Maracha Hospital even if it is often difficult to define ‘a couple’ in the context of polygamous marriages, or for clients who, perhaps secretly, have several sexual partners.

One crucial challenge is 'disclosure'. Human rights approaches to HIV/AIDS have helped forward the principle that it is the individual's prerogative to disclose his or her HIV positive status to others (Yeatman 2007; de Cock et al. 1998). However, at the same time, getting a client to disclose to his or her sexual partner(s) is considered a central component of being able to protect that client's partner(s) from HIV infection or re-infection. Consequently, 'empowering' a client to disclose is a crucial, but complicated process that the counsellors initiate once someone tests positive for HIV.

In the AIDS clinic in Maracha, the majority of the clients are women, and Joyce frequently asked the female clients whether they had disclosed their status to their husbands and what their reaction or reply had been. Quite often the female clients replied something along the lines of 'Yes I did, I also told him to come and test, but up to now, he has not come' (Fieldnotes 24 Apr 2009). Joyce was rather frustrated in relation to encouraging disclosure among the clients; "disclosure is a bit difficult, I've failed to manage it, whether you do counselling, you are wasting your time, at least some can respond, but others will not" (Interview 12 May 2009). To one pregnant woman who had just tested positive, Joyce insisted that she had to disclose for the sake of treatment efficacy:

'it's not ok that when I give you drugs, you take it alone because the rate of which the virus reproduce will reduce in you, but remain high in your husband, yet you stay together, that one will not work for you. Be encouraged to speak to your husband and you come back on Friday and tell me whatever reaction your husband has taken' (Fieldnotes 24 Apr 2009).

In my interviews with the KCCC counsellors most of them emphasised that disclosure is a process that they 'slowly by slowly' have to help clients go through. They pointed out that especially for women disclosing might have disastrous social effects. However, in one of the few counselling sessions I observed where disclosure was discussed the techniques used were somewhat similar to Joyce's treatment-related instructions. This session was a post-test counselling session with Anthony and a man who had just tested positive:

Anthony: *Are you ready to disclose your status to anybody?*

Client: *Nobody. I can't disclose to anyone*

Anthony: *But non-disclosure will do you more harm than good. Why don't you disclose to your wife?*

Client: *She is pregnant and I am scared she will run away from me*

Anthony: *If you don't disclose your status to your wife you will have problems. Because if you are to start on ARVs then your behaviour has to change. The number of times you play sex will have to reduce. If you have been playing sex*

daily it will reduce to maybe once a week or twice a week. Your wife will start suspecting infidelity. So she might also decide to have an extra-marital affair because she doesn't understand you and your behaviour change. So I advise you to disclose to your wife. Secondly if you continue having sex with her very frequently then you will have re-infection, it means the virus load in your blood will increase and go higher. Therefore I suggest that you disclose to your wife. You can also bring her here for testing by her telling her that when I went for TB treatment, the doctors advised me to go with you for a blood test (Fieldnotes 5 Jan 2009).

In this session, Anthony placed emphasis on ARV treatment requirements and speaking to the client's self-interest with regards to avoiding re-infection, but he also emphasised the complications to the relationship a lack of disclosure may bring. Reducing the frequency of sex was a method to reduce the risk of re-infection presented to clients taking ARV treatment as an alternative to abstaining or using condoms. But in this case Anthony actually presented the method as an unquestionable fact. Again it is noticeable how the counsellor speaks only to the client's self-interest, and not for example to a possible concern with protecting the wife or their baby from infection. The interaction also illustrates how Anthony with rather leading questions was attempting to make the man reach a certain 'informed decision'.

Another crucial relationship challenge is HIV discordance: When one part of a couple is HIV positive and the other is HIV negative. Most counsellors agree that counselling discordant couples is one of their greatest challenges. Rose for example said:

"The most challenging situation is when a couple comes for counselling and . . . they come out discordant, it becomes challenging in that, one tends to be blaming another, that you are the one who brought the disease . . . and it takes a counsellor some time to unite them, to make them overcome such a problem" (Interview 27 Jan 2009).

The KCCC counsellors often emphasised that one of their central concerns when counselling discordant couples was to ensure 'the marital unity'. Damian commented that discordant couples were a great challenge to the Catholic Church's concern with protecting the family (Interview 19 Jan 2009). Apart from ensuring marital unity, counselling discordant couples involves complicated questions about how to ensure responsible sexual conduct.

In another session, Anthony counselled a woman who had just tested negative, yet she knew her husband to be positive. They discussed in length whether she could encourage him to use condoms and whether the condoms are 100% effective. The woman was adamant that she could demand condom use from her husband or otherwise she would separate

from him. When asked who she would disclose her status to, she replied that she would tell her husband: 'I'll show him the paper. Since I have to be careful with him, I have to tell him'. Anthony then informed her that in KCCC they do not let people take the paper with the lab results on. The woman then asked 'I understand that if couple tests they have to give you the results together'. Anthony confirmed that this was indeed their policy. He then encouraged her to bring her husband, so that they together could 'plan what to do'. He informed her that the result that 'had come out' was called discordance and that KCCC partner with some 'experts' in discordance, which could help her and her husband (Fieldnotes 12 Jan 2009).

The example illustrates some of the reasons why getting couples to test together is a central concern for the counsellors. When a couple comes together, it is possible in fact to disclose one partner's status to the other partner, and it is also possible to bridge a certain credibility gap of actually believing that the status is true. In the partner organisations KCCC refer discordant couples to, the couples can be provided condoms and get information on how to use them. In Maracha Hospital's AIDS clinic, they do not have such partners they can refer discordant couples to.

Following the rules of ARV treatment and Positive Living

The above examination of counselling practices in KCCC and the AIDS clinic in Maracha Hospital have illustrated how the counsellors' attempts to promote a certain kind of responsible self-government among their clients are connected to bio-political ambitions to 'save lives with ARV treatment' and reduce HIV prevalence. With this connection comes a tension between discipline and self-practice; among counsellors, managers and doctors there were doubts and frustrations over whether non-directive counselling can achieve the necessary 'responsibilisation' of clients. This tension becomes even clearer when I in this final section turn to one of the most central concerns in the context of ARV treatment: adherence. For the sake of ensuring the proper adherence to ARV medicine, not only counselling is employed but a range of other disciplining and monitoring methods. In this context, following the treatment instructions of ARV medicine appears to be combined with Positive Living recommendations in ways that effectively turns Positive Living into 'rules'.

Treatment instructions in Maracha Hospital AIDS clinic

Joyce' counselling-consultations are brief sessions, which, as indicated above, consist primarily of giving the clients advice and instructions. In her sessions, the practical recommendations of Positive Living turn into rules of conduct for clients on treatment. I believe it is primarily the limited time

and the medical context of Joyce's consultations that contributes to this phenomenon. Joyce is alone in handling about 10-20 clients on each clinic day in sessions that are to encompass clinical consultation, counselling, adherence monitoring and drug dispensing. In an attempt to minimize the clients' waiting time, she tries to keep each session rather short. She told me that she had recently learned how to minimise the clients' waiting time and reducing the time each session takes as part of the Quality Care Improvement initiative⁹⁹ (Interview 12 May 2009).

One example will further illustrate how Joyce concentrates on giving easily repeatable Positive Living instructions to the clients. In this session Joyce took a bit longer than usual going over 'the instructions' of ARV medicine, because this female client had 'defaulted' on the ARV treatment.

Joyce: What do you know of ARV? Remind me some of the messages I gave you about ARV?

Silence for some time

Client: I was taught to have a person that would remind me to take the drugs, but I answered I have been taking these drugs for long, so I know how to. . . . I remember there are two types of ARVs, one big and one small.

Joyce: What other types of drugs were you given? These ARVs are of several types, not only two types. You started with this one (showing the pill); one in the morning and one in the evening. For septrin, you take it once a day, not twice. For this ARV, 8 a.m. in the morning and 8 pm. in the evening, you don't change the time. In the afternoon, if you allocated that time for septrin, you don't change that. What else did you learn?

Client: Before taking this drug, you have to eat food.

Joyce: If there's no other food, you should eat fruits and then take this drug. It will also help you. You have mentioned two issues: time and food. What other issue can you remember?

The client could not remember any other issues, so Joyce concluded:

Joyce: Once you're taking this drug, you should not take alcohol, smoke and not play sex unnecessary, if it's with condom, it's ok. Once you have started taking this drug, you're advised to use condoms simply because if you have sex you will add viruses to yours, yet you have started taking the drugs to help you reduce the virus (Fieldnotes 17 Mar 2009).

So towards the end of the session, after 'hearing' the client several times, Joyce concludes with a generalised instruction on Positive Living, reminding the client about those 'messages' she apparently had forgotten.

⁹⁹ For example if a client has more serious medical complaints which requires the attention of a doctor or a clinical officer, Joyce will now immediately send the client there, and then handle the rest of the things she has to handle with that client, when the client returns with a possible diagnosis and prescription from the doctor or CO. In the meantime she can handle other clients.

These kinds of treatment instructions can be paralleled with the tendency Silverman identified in his studies of HIV counselling in the UK and the US in the 1990s to provide “(t)runcated, non-personalized advice sequences”. He argues that these are usually far shorter than other counselling formats, which is “an important consideration for hard-pressed counsellors” (Silverman 1997: 35-36). Being pressured in terms of time is certainly a consideration for Joyce. Translating all the aspects that Positive Living ideally encompass into easily repeatable ‘instructions’ enables the counsellor to cover many topics in a short time, and provides an easy way to check whether the clients have understood how they are supposed to conduct themselves (and for clients it minimises their waiting time in the clinic).

However, apart from time, Joyce also explicitly ties these instructions to what is required ‘when on treatment’. It is significantly in the context of ARV (and septrin¹⁰⁰) treatment requirements that Positive Living is no longer that much about having a positive attitude towards life, but about following these rules of self-conduct, because otherwise the treatment may not be effective.

ARV treatment only bring miraculous recovery if you follow the rules

In KCCC, the counsellors do not provide treatment instructions to quite the same extent as Joyce, and there is a generally a wide spectrum of counselling provided by the different counsellors and in different situations. However, in the way clients are educated to manage their CD4 cells, there is a similar transformation of Positive Living recommendations into ‘rules of the ARV treatment’. In the ART enrolment session clients are taught the adherence rules of ARV treatment together with advice on how to protect ones CD4 levels. Jagwe presented adherence to the ARV treatment as rules in the following way:

I want to give two rules of these ARVs: You have to take it daily, this one I think you know, and you have to take it at the same time. They discovered if the virus gets a gap, it can become resistant. There is what they call adherence (Fieldnotes 14 Jan 2009).

In the ART enrolment sessions Jagwe usually begins with asking the clients about ‘the enemies of the CD4’, then he goes over the different types of ARV medicine, the rules of ARVs and then possible side-effects and what to do in case of side-effects. In this way the need to protect the CD4 cells is tied to achieving treatment success. For example in one session, after going over the enemies of the CD4, Jagwe asked the clients

¹⁰⁰ In Joyce’s consultations, she did not distinguish between ARV medicine and septrin when it comes to their rules.

‘what do we do to get the CD4 up? One of the clients replied: ‘feed well, stop worrying’. Jagwe then said:

. . . This situation of worrying, you should know that death is normal, you may die of something else, someone negative may die before you. The more you worry, you find you loose yourself for working, you loose appetite, you loose hope. Once you loose hope, how will you be helped? We’re going to help you fight the enemy.

. . .
The virus keep multiplying, there’s no way of stopping it. That’s why you need the drugs. We thank God for the people who invented these drugs. We’re going to fight the HIV, you will help by swallowing the medicine. We get the medicine from wherever it comes from, keep it here and then give it to you. It’s like football, you’re a striker, you’re just going to shoot to score. You’re role is to take the medicine. The pharmacy asks for 1,000 per month.

The rules of the ARVs, there is no devil in this. You see somebody who come when they’re badly off, who have really recovered. ARVs is the only drug who has come out who can prevent the virus from multiplying (Fieldnotes 17 Dec 2008).

Thus apart from not worrying, eating well and not overworking yourself, following the rules of ARV treatment is what the clients have to do ‘fight the enemy’ who is ‘eating’ their CD4s. Jagwe introduces a figure of joint responsibility here: ‘the white people’ bring the drugs, we give them to you almost for free and then you only have to make sure to follow the rules.

What was central in Jagwe’s sessions and other on-going counselling sessions was the way clients were taught that the ‘miraculous’ potential of the ARV medicine can only be realised if you follow the rules well. This feature is also prevalent in Joyce’s instructions; ‘when you take this drug, you are not supposed to...’. In a CD4 result counselling session, Daniel informed the client Assumpta¹⁰¹ that her CD4 count had dropped to 147 and it was therefore time to start begin ARV treatment. They discussed the implications of starting ARV treatment, and Daniel also explained to her the importance of adherence:

There are different drugs, some are taken twice daily, some once. It depends on the doctor’s assessment. No matter twice or once, time! If you take it at 8.00 in the morning, it must also be 8.00 in the evening. If you miss a dose, you give the virus a chance to multiply. If you keep missing doses, you may develop resistance. Then you will have to change drug regime. If you keep developing resistance, you may find we have no more regiments to offer you’ (Fieldnotes 15 Dec 2008, session in English).

If clients develop resistance, they will have to change from a first-line to a second-line ARV combination. What Daniel clarifies to Assumpmta here, is that given the limited treatment options with antiretrovirals and the limits

¹⁰¹ I later interviewed Assumpta and her case is discussed in chapter 9.

to what medicines are available in a clinic like KCCC, the consequence of not following the rules is eventually to run out of treatment options.

As mentioned in chapter 2, the fact that medical substances can be simultaneously harmful and beneficial is recognised in many different healing traditions. The techniques used in counselling in both KCCC and Maracha Hospital to encourage clients to follow the rules of ARV treatment helps to constitute ARV medicine¹⁰² as extremely potent: if you follow the rules well it can be no less than miraculous, but if you do not follow the rules well, the medicine can in turn be poisonous or even deadly. In the words of the KCCC community worker Proscovia: "you tell them this drug is for life . . . if he doesn't swallow it well, then they will be loosing their lives." (Interview 13 Feb 2009).

The notion that some drugs have non-negotiable rules is remarkable in the Ugandan context, where pharmaceuticals have become a kind of 'folk medicine' (Whyte 1998). In fact, Whyte argues that "(m)ost people in rural Uganda have not been socialized to accept the professional monopoly on the means of health care, nor the rights of experts to make decisions about what is best for their patients" (Ibid: 330). In this context, I argue that we can interpret the counsellors' treatment instructions as an attempt to vest authority in the ARV medicine, rather than relying on their authority as health professionals. It is because of the potency of ARV medicine that you have to follow the rules, not because I say so.

Disciplining and monitoring techniques

Apart from the way the counsellors try to 'reponsibilise' the clients to follow the rules of ARV treatment and Positive Living with instructions, advice or CD4 education, their practices are also part of a range of disciplining and monitoring techniques. In both KCCC and the AIDS clinic in Maracha Hospital, to ensure that clients do follow the rules, a number of disciplining mechanism and performance indicators are also put in place. This illustrates how for the sake of saving lives with ARV treatment, the organisations cannot only rely on clients making their own informed decisions.

The disciplining and monitoring techniques in the two clinics are similar to those employed in other ARV treatment programmes. First there are the appointments. The first two weeks to one month on ARV treatment are critical, since serious and even deadly side effects can occur (therefore in most clinics, the first dosage of ARV drugs is given for two weeks). If the client does well the first two weeks, the dose can be increased to one month

¹⁰² In Maracha hospital, since ARV medicine and septrin are not distinguished, these rules effectively become rules of AIDS medication generally.

and later two or three months. However, continuing to require clients to come back for regular check-ups on specific dates illustrates a general concern with disciplining clients to ‘follow time’ and not to interrupt treatment. The disciplining aspects of appointments is reflected by how septrin in some clinics, like in Maracha Hospital, is provided in similar ways (and according to similar rules) as ARV treatment, as a way of monitoring if the client is capable of following a strict treatment regime¹⁰³. It is also reflected by how failure to honour appointments may be punished, and how clients who successfully honour their appointments are rewarded with having the dosage period increased, to three months in KCCC and to four months in Maracha Hospital in one particular instance. Ironically, the fact that clients in most cases can only get a new batch of drugs if they show up at the clinic for their appointment means that some clients miss taking their medicine for several days if they, for various reasons, are unable to come to the clinic on time, or to send someone on their behalf¹⁰⁴.

Secondly, the appointments are also defined as necessary for ‘follow-up’. Home visits constitute another method of follow-up, which will be discussed in chapter 8. ‘Follow-up’ is not only about checking the medical state of a client, but about checking more broadly that the client follow the rules of ARVs. To do so a number of performance indicators are employed by the counsellors, and in KCCC also the doctors. In Maracha Hospital, Joyce uses the clients’ weight and symptoms/diagnosis of opportunistic infections to monitor not only their medical state, but also how well they are following the rules of AIDS medication. As she said:

“When one takes treatment well, you’ll find that the opportunistic infections, they reduce, and then they gain weight . . . , if they’re having frequent opportunistic infections it means they are not adhering well . . . others may mix taking the drugs with alcohol or smoke like that, mixing drugs with alcohol will not really help you” (Interview 12 May 2009).

In one session, a man who had come late for his appointment explained that he had borrowed pills from a fellow client in order not to miss any dosages. His weight had also dropped from 56 kg to 52 kg and he said that is was because he was busy ‘digging’. Joyce reprimanded him for his failure to follow the rules well: he missed his appointment, borrowed drugs and was ‘overworking’. And then she decided to only give him drugs for one month

¹⁰³ In KCCC, non-ART clients were not systematically followed-up by counsellors and community workers. However, the coordinator of the home-based care programme, Mr. Bisase told me that they now wanted to include home visits to non-ART clients precisely to check how those clients performed on septrin (Interview 11 Feb 2009).

¹⁰⁴ In KCCC, the community workers are supposed to assist in such situations and KCCC also have two cars to bring bedridden clients to the clinic for their appointment. This point is further discussed in chapter 9.

instead of his usual two months. She said that this was because he did not have enough money to pay the consultation fee (Fieldnotes 20 Mar 2009). However, not being able to pay the fee is not something that clients are usually 'punished' for. Quite on the contrary Joyce repeatedly tells the clients that not having enough money for the fee is not an excuse for missing your appointment. To a woman taking septrin, who had missed her appointment date with over one month, Joyce said: 'You missed drugs for one full month, I'm going to again give you drugs. If you miss again, I'm going to cancel your name. Even if you don't have money you come, I give you the drug, you come and give the money afterwards' (Fieldnotes 28 Apr 2009).

Thus adjusting the dosage can work as a punishment or a reward for respectively poor and good performance, and poor performance can be ultimately punished with being taken off the programme. One female client received ARV and septrin pills for four months, even if she had in fact missed her appointment date with over two weeks (the client explained that she still had pills remaining). After the consultation, Joyce explained to me the client was a nurse living in Arua who preferred to come to Maracha Hospital, because she found the waiting time in Arua Hospital's AIDS clinic too long (Fieldnotes 12 May 2009). The fact that nurse was not quite so strictly 'disciplined' as other clients, may reflect the fact that as a health worker, Joyce had more trust in her capability to conduct herself according to the rules of AIDS medication.

In KCCC, great emphasis is placed on monitoring ARV adherence in different situations. When an 'ART client' comes for his or her appointment, the client first sees his or her assigned doctor. The doctor asks the clients how he or she is taking the drugs and whether he or she has missed any doses. Based on this, the doctor records the client's level of adherence in his or her file. Towards the end of my fieldwork I spent one day with a doctor handling only ART clients. One woman who had missed her appointment came into the consultation room apologising:

Client: *I'm sorry, I've never done it before*

Doctor: *What did you say when you started this drug, 'I will always come for my appointments, no matter what. Did the counsellor make you swear that?*

Client: *I'm sorry*

Doctor: *If it happens again, I won't see you again* (Fieldnotes 26 May 2009).

This interaction vividly reflects how appointments function as a disciplinary mechanism. During home visits, community workers also ask the clients how they are taking the drugs and sometimes they also count how many pills are remaining as a way to check whether the clients have

missed any dosages (I will discuss this further in chapter 8). In on-going counselling sessions, counsellors may also ask such questions, and ask ‘what reminds you to take the drug one time?’ (Fieldnotes 11 June 2008). What was rarely discussed in KCCC is that even with this kind of monitoring, the doctors, counsellors and community workers do in fact not know for sure whether the clients are actually taking the pills everyday at exactly the same time. Daniel, however, mentioned that all these methods constitute only indicators of performance:

“I can’t even tell you that whatever we tell people is what they do, because we are not there, because you ask someone, did you swallow your medicine? Says I did, and what do you do next, the only maybe factors which help us to know is the performance then maybe someone is not, the CD4 is not improving, the weight is constant, you see sicknesses are coming on and off that can be an indication that the individual is not adhering to treatment, but the best we can do is to explain, take one tablet once a day, twice a day, and maybe even send there someone to do pill counting, someone does that and says everything is ok, but someone could be picking one tablet every day and throws it away (chuckling)” (Interview 3 Feb 2009).

Daniel’s point illustrates the general doubts and suspicions about whether clients do in fact follow the rules well. And it reflects the failure of counselling as a method to get clients to ‘admit’ to having problems with following the rules. When counselling and other forms of follow-up fails, there are, however, medical indicators, which will reveal a client’s poor adherence. The indicators are similar to the ones used in Maracha Hospital, except for the possibility of also using the CD 4 cell count. In this way, the CD4 count becomes a key marker of proper performance as a client in KCCC.

Evaluating the performance of counsellors

The indicators monitoring each client’s performance are in both clinics combined into programmatic indicators, which are used in reports to their donors. These statistics on adherence, mortality and enrolment rates can in turn be used in the donors’ presentations of the number of lives saved.

In KCCC, setbacks in adherence and mortality rates and an increasing number of clients ‘lost to follow-up’ were frequently used by the management to pose questions about the performance of both the counsellors and the community workers. In the beginning of 2009, in connection with the development of a new 5-year strategic plan, the management of KCCC asked each department to develop a work plan for 2009. This work plan was to include quantitative targets, as well as qualitative standards. After presenting the idea with these work plans at a morning praise, the executive director went on to talk how about the donors were asking questions about the usefulness of the community workers: ‘. . .

your patients and your performance have gone down according to the indicators we have put down: a) many of them have disappeared why? That means it's either the follow-up or the recruitment, b) so many ART patients have died, these people are not supposed to die' (Fieldnotes 27 Jan 2009).

The performance indicators were part of a pressure on the counsellors (and the community workers) to produce certain behavioural results among their clients. In line with non-directive counselling methodology, the counsellors talked about this pressure as a lack of recognition of their work and a lack of appreciation for what counselling meant. Olga explained how she had discussed with counsellors from other organisations how their work was never appreciated:

"I've just been in a workshop where we were with fellow counsellors, but the same problem they are saying that counsellors have never been appreciated, our work has never been, has never been visible, they always says 'counsellors we are doing nothing, counsellors we are doing nothing', somebody who always demoralises you, it's very bad" (Interview 5 Feb 2009).

In response to this lack of recognition, the counsellors seemed concerned with documenting and proving that they did important work. In response, Daniel and some of the other counsellors had developed a Counselling Data Collection Tool. The form was to be filled in connection with or after each counselling session so that the counsellors could gather data on how many clients they counselled, who these clients were, and the issues that emerged in counselling. The form also had a question on how the clients had 'benefitted from counselling'. After filling the forms, the data was entered into a database. During a preliminary feedback meeting with the counsellors, Daniel asked for my comments and feedback on: 'What can be done to make sure that counselling has impact? And what can be done so that counselling is felt?' (Fieldnotes 11 Feb 2009). These questions reflect not only a concern with documenting the counsellors' contribution, but also that the counsellors shared some of the doubts and frustrations over whether counselling could achieve the proper 'responsibilisation' of clients.

For the AIDS clinic in Maracha Hospital, performance indicators were also introduced with the Ministry of Health's recently started 'Quality of Care Improvement Initiative'. With this initiative a number of performance indicators had to be collected for each client during each consultation. There were four core indicators: signs of TB, WHO stage, adherence rate and signs of opportunistic infections. Joyce's work was thus evaluated according to similar performance indicators as the KCCC counsellors. But in my experience, in her relations with the hospital's management she did not face the same suspicion that her counselling was not effective. The hospital management found that the clinic was generally so constrained in

terms of human resources and ability to offer additional services (such as home-based care and nutritional support), that the poor adherence rates were not be surprising to them (Interview 22 May 2009).

Chapter conclusion

Counselling as a method to govern the conduct of people living with HIV/AIDS in the context of ARV treatment face contradictions in KCCC and the AIDS clinic in Maracha Hospital. Counselling is meant to enable clients' responsible self-government by exploring 'the truth of the self' and guiding each individual according to his or her own truth. But in the face of practical and social difficulties and in the context of bio-political ambitions to save lives with ARV treatment, there are doubts and frustrations over whether such non-directive counselling can achieve the proper 'responsibilisation' of clients. In this context, counsellors tend to provide generalised advice rather than attempting individualised, introspective explorations. More precisely, they focus on educating and disciplining clients to follow 'the rules' of ARV treatment.

Counsellors attempt to incorporate Positive Living practices as a technique of self-transformation that can instil in clients a desire to follow life-prolonging practices. Some of the KCCC counsellors formulate such techniques in Christian terms as a matter of reconciling an HIV positive status with continued worth in the eyes of God. But in the context of the didactic and disciplining focus of counselling, also Positive Living is mostly promoted as rules of conduct rather than as an ethical self-practice. This phenomenon is pronounced in the AIDS in Maracha Hospital where such 'treatment instructions' becomes a way for Joyce to handle an enormous workload on her own.

As a matter of ethical subject formation the counsellors thus tend to promote the notion that to live well with HIV/AIDS is to follow the rules of Positive Living and ARV treatment. The appropriate care of the self promoted in counselling thus revolves around how to follow the requirements of the treatment and monitor one's progress in doing so with CD4 counts or weight gain.

7. Negotiating holistic care in the context of neo-liberal development rationalities and ARV treatment scale-up

Introduction

If living well with HIV/AIDS is a matter of following the rules of ARV treatment and Positive Living, does being a client come with entitlements to assist you in following the rules well? Does Positive Living also constitute a set of rights to enable a life-prolonging lifestyle as ‘the TASO philosophy’ suggests? As illustrated in chapter 5, all the three Catholic organisations adhere to at least a basic holistic care rationale, which posits that living well with HIV/AIDS in Ugandan settings cannot be achieved with medicine alone, but also requires social and perhaps spiritual assistance. However, in the context of scaling-up ARV treatment, new questions emerge about whose responsibility it is to provide such care.

This chapter analyses how the rights and responsibilities of ‘therapeutic citizenship’ in the realm of the social and material is worked out in the three Catholic organisations. The chapter begins with exploring the fate of some of the different interventions started by KCCC in the 1990s as part of an integrated, holistic AIDS response. The AIDS clinic in Maracha Hospital and the HBC programme coordinated by Ediofe Health Centre are included in the following sections, which first look into the debates about discontinued food support programmes in both Kampala and Arua. Thereafter, I analyse the different ways employees in the three organisations approach the question about who is responsible for addressing ‘the social issues’ of ARV treatment success (cf. Richey 2011). I show that in line with neo-liberal development rationalities, there is in all three organisations an emphasis on educating and counselling clients to find ways to help themselves. Consequently, it becomes the client’s own responsibility to address any socio-economic barriers to treatment success.

Developments in holistic care interventions in KCCC

In my interviews with programme coordinators and in the focus group discussions, KCCC was often praised as an expert and pioneer in holistic care. But as I started observing counselling sessions and home visits in December 2008, the counsellors and community workers’ limited ability to assist clients with socio-economic problems struck me. Especially during

home visits, clients often expressed concerns over having nothing to eat, inability to pay school fees or to pay rent, and some insisted that if they could only get some capital they could start a small business to support themselves. Even considering that some of these pleas may mostly have been brought up in the conversation on account of my presence, it was remarkable to me how the community health workers usually met such appeals with silence. Since supposedly KCCC offers social support services meant to address at least some of these issues.

It may very well be the case that the ideals of holistic care have always been far from the experience of clients and employees. However, according to my interviews and the experiences of people who have been clients in KCCC for many years, it is clear that, from the 1990s to today, a number of changes have taken place in some of the programmes meant to ensure an integrated holistic care response. For one, the sheer growth in KCCC's number of clients poses a challenge to providing integrated, holistic care. Reflecting an experience of KCCC's services changing, an elderly woman, called Fatuma, who had been a client in KCCC since 1999, said on a home visit: 'It used to be easy. I think most of you are new, they used to give house rent, they gave sewing machines . . . ' (Field notes 22 Jan 2009)¹⁰⁵.

This section analyses developments in KCCC's portfolio of holistic care programmes, which can elucidate my experiences with disconnection between ideal and practice. I consider the dilemma outlined in chapter 5 between helping 'the whole person' or 'the whole community', and the questions about sustainability this dilemma also bring.

From social services exclusively for people living with HIV/AIDS to general community support

As outlined in chapter 5, the expansive rationality of holistic care led KCCC to develop a wide portfolio of social support programmes. But in a slum area like Kamwokya, and a general context of persistent social inequalities and limited social services, providing such service raise questions about whether it is justifiable only to offer such services to people living with HIV/AIDS. Consequently a number of programmes initially started to address their needs were opened up to the general community of Kamwokya and beyond.

This was for example the case with the Child Welfare department. According to the coordinator, Maria Nakayima, as the programme grew they realised that it is not only people living with HIV/AIDS who have vulnerable children. They met children who were distressed that they did not qualify for support because they were not orphans. So, presently they

¹⁰⁵ I will discuss Fatuma's situation in more detail in chapter 9.

also focus on other vulnerable children, not only AIDS orphans or children of people living with HIV/AIDS. Maria mentioned that this focus was also in line with government's OVC policy (Interview 22 Apr 2008). As mentioned in chapter 5, the Child Welfare department's core intervention is school fees support. However, the waiting list to access this support is considerable. In the interview, Maria identified one of their key challenges being an overwhelming number of people seeking their services. She said that every day, five to ten new people come to the office seeking support, and that many of these people come from outside Kamwokya (Interview 22 Apr 2008).

As the programme moved from helping 'the whole HIV positive person' to the 'whole community', the limitations of trying to help the whole community became apparent. They cannot help every vulnerable child in Kampala. In the process, questions necessarily emerge about who is 'deserving' – who are most vulnerable? Maria claimed that the social workers in the department tried to identify the 'most vulnerable children', but that they were unable to assist all of those in need (Interview 22 Apr 2008). The waiting list is thus a way to prioritise; those who came first are supported. According to Anthony, children of KCCC's clients, referred by the counsellors or community workers, are put on top of the waiting list. But still the school fees support reflect how the opening of the service to the general community may result in the access becoming more limited for the children of people living with HIV/AIDS. Anthony insisted that the counsellors would always refer clients with social problems to KCCC's other departments.

“. . . we have the skills of referring, because this is counselling department,, but issues concerning school fees, we always refer our clients to the Child Welfare department, because this department is concerned., we refer them there, they document their issues . . . when funding come they will first consider our clients who are referred from this department” (Interview 2 Feb 2009).

However, during my observations of counselling sessions and home visits, I experienced only very rarely that clients who complained of socio-economic problems were referred to any of KCCC's other programmes, such as the Child Welfare department for school fees support, the vocational training centre, or the SACCO to access loans to start a small business. The supposedly integrated nature of KCCC's programmes did not seem to be effective in most cases. Perhaps this was simply because many of the social support services are not easily accessible to clients; the waiting list to school fees support is endless, support for house rent has been stopped, the SACCO came with new strict loan criteria and the nutritional support was discontinued. The community health worker Ephrance, who had a very frank demeanour, told me that clients

complained of not being able to access school fees support, since they knew “those people who send drugs, they send money for them” (Interview 11 Feb 2009). When I asked Ephrance if clients were not able to access support from the Child Welfare department, she assured me: “They give them only what? Only drugs, and even some they don’t have food, balanced diet, that’s why people, they remain weak” (Interview 11 Feb 2009).

Ephrance’s statement indicates that clients are asking for school fees support on the basis of an entitlement, which comes with their therapeutic predicament, or perhaps rather to a certainty that the donors have funded assistance meant for them. On a home visit, after a client had asked me about what comes out of my research, she asked me ‘do they know in outside countries who we are?’ At first I thought she was worried about protecting her privacy, but then she said: ‘I was told at KCCC that we take pictures of you and take your name for the donors, because there are benefits for those on ART’ (Fieldnotes 23 Jan 2009). The notion of benefits for people living with HIV/AIDS, which were no longer available or did not materialise was a common theme in my fieldwork in KCCC, as the following sections will illustrate.

Restructuring of microfinance services

Like the Child Welfare services, KCCC’s microfinance programme was changed from targeting only people living with HIV/AIDS to being open to the general public. The case of the microfinance programme reflects how holistic care rationalities have had to be increasingly negotiated with sustainability concerns in KCCC.

In 2004, the microfinance programmes was transformed into a savings and credit co-operative (known as a SACCO). According to some informants the problem with the previous microcredit programme was that the clients perceived the loans as a gift, because it was from the church, and therefore it was not paid back or even invested. According to Anthony:

“we used to give out money grants 500,000, 300,000, 200,000 . . . but this . . . was creating an attitude in people, this is Sr. Miriam Duggan’s money, this is church money, you give money someone will put in the hair, you give money, you visit the business, the business is down” (Interview 2 Feb 2009).

As a response to the experience that giving grant was creating a ‘dependency’ attitude, KCCC decided to establish a SACCO instead. In the SACCO members have to bring savings before they can take a loan. According to the director Francis: “It was transformed, because we wanted the members themselves, the people whom the grant were being given, to participate . . . because when you become a member, having paid the shares, the entry fees, you become a co-owner . . . of the society”

(Interview 2 May 2008). According to Anthony, the idea of transforming the microcredit programme into a SACCO in order to ensure its existence actually came from the donors:

“now they brought their ideas, in fact it was coming from the donors, they made an evaluation that said, we have given millions of money, enough is enough, then they said we are now giving you a final grant and try to see that this money is being developed, and we started the what, the empowerment project, the SACCO, when you see now how SACCO has grown...people get money, but they are forced to revolve it back” (Interview 2 Feb 2009).

According to the rationalities presented in this quote, stricter loan and repayment requirements, and a responsabilisation of clients through ‘ownership’ of the programme was a requirement to keep the programme running. Without such measures the programme would just continue to be an endless ‘hand-out’. The quote from Anthony also reflects that the donors required a responsabilisation of KCCC as well. The donors have appeared to push for a reorganisation of the programme, which followed common sustainability rationalities of only providing funds that can ensure independent and lasting ‘community’ development.

After the restructuring, you had to open a savings account in the SACCO and become a ‘member’. The SACCO is open for anyone residing in Kampala district. After two months, you are eligible to take a loan in the ratio of 1:4 to your savings. To apply for a loan you need to provide security and have one or several guarantors. However, according to the director, people can borrow small amounts like 100-200,000 shillings, without having to provide security¹⁰⁶. For this amount, a guarantor would be enough, especially if the guarantor is a person well known to them, who lives permanently in Kamwokya. If you fail to pay back your loan on time, the bank first approaches your guarantors (who can be required to pay on your behalf). The bank can also freeze your savings and eventually seize assets from you. According to the director, 25% of their members are people living with HIV/AIDS (Interview 2 May 2008).

For most of the clients I interacted with, the loan and repayment requirements seemed unattainable, or even frightening. On home visits with Beatrice Asiimwe, who is a client herself, we visited a woman living in a small 1-roomed mud house in Kamwokya. The client complained of having problems paying rent, and also said: ‘Even food is a problem, because I’m not working. I would like to work, but I don’t have capital. That causes stress. School fees is also a problem, I have a child in

¹⁰⁶ The general perception among clients, community workers and counsellors was though that to take a loan from the SACCO you need to provide security. Also, the application form appears to list ‘security’ and ‘guarantors’ as requirement you have to meet.

university.’ I asked her and Beatrice if she could not get a loan from the SACCO. They both answered in a tone suggesting that would obviously be unrealistic. Beatrice said ‘in SACCO, you first have to save and then you need security like land titles, or a TV, fridge or something like that’ (Fieldnotes 6 Jan 2009). One of very few clients I interacted with, who had actually joined the SACCO, was a woman staying in Mulago. She said:

‘I want to get a loan from Kamwokya, but I don’t have the deposit to take there. I want to start a small business. I have an account there, but I have never added anymore. When I want to add, the school fees come, then feeding.’ (Fieldnotes 13 Jan 2009).

While some clients find it unrealistic or impossible to bring enough savings and provide security, some apparently fear the consequences of perhaps not being able to repay the loan on time. The community health worker, Doris contended ‘people fear, if something happens the bank will want their money’ (Fieldnotes 12 Dec 2008).

During a preliminary feedback meeting with the home visiting team, I asked the community workers to discuss what can be done to improve the clients’ access to capital or to other opportunities for starting income-generating activities. Their discussion is quite instructive of the debate between different rationalities for providing social support services to people living with HIV/AIDS taking place in KCCC. Below are selected excerpts of this discussion:

Beatrice N.: *Me, I request if these people can be helped to get loan with low interest and no security needed, they’re just staying in somebody’s house, they have no property. In SACCO, they want security, and the interest is very high.*

Anna: *It’s good to give them capital. But they need to be trained, they think such money is free, ‘it’s for the sick’.*

Mr. Bisase (the coordinator): *They see this money as a grant, will that be sustainable? It was tried before, but it didn’t work.*

...

Matilda: *That thing has worked in SACCO, but most of our people fail, you need 50,000 and the interest is uniform, and they need guarantors. And for us we couldn’t be guarantors. Even those we stood for as guarantors, we ended up paying. So they need serious sensitisation.*

Cecilia: *Me, I have a criterion they could use, it should come as a grant, they give it in a group, they put regulations for the people who are sick. There are people who want to work, they have the heart to bring the money back, but because of those who don’t bring back the money, they got problems.*

Beatrice A: *Why should we pay the same interest and provide security? Some of them have just recovered, trying to pay back such a loan will cause stress* (Fieldnotes 21 Jan 2009).

There is a debate here between two rationalities. There is the rationale that people living with HIV/AIDS need social support services specifically tailored to them, in order to help them recover. On the other side there is the rationale that services tailored specifically for people living with HIV/AIDS will produce the attitude that because they are HIV positive, they are *entitled* to special treatment and ‘free things’. In the context of a microcredit programme such an attitude, as KCCC experienced with the former programme, is ‘unsustainable’, because it creates the perception that since the loans are ‘for the sick’, they do not need to be paid back.

The coordinator of the home-based care programme, Nabeel Bisase, is one of the few Muslims working in KCCC. He is a well-educated¹⁰⁷, elderly, quite distinguished man, who takes pride in fulfilling his responsibilities as the coordinator, which he has been since 2007. He was formerly a local leader in Kamwokya, and in that position became involved in the early efforts of KCCC¹⁰⁸. Mr. Bisase explained to me that it was because of the previous repayment problems that the new SACCO is not open for clients alone; ‘clients are encouraged to take loans on the same terms as others. There have to be strict measures to make sure people bring back the money’. Nonetheless, he agreed with my observation that now, with these ‘strict measures’, many clients cannot access loans from the SACCO (Informal comm. 19 Dec 2008).

Debating discontinuation of food support

In all the three Catholic organisations the discontinuation of food aid programmes was a frequent topic of discussion. In the following sections, I analyse the different rationalities at play in these debates, in order to illustrate how holistic care and neo-liberal development rationalities are negotiated in the three Catholic organisations.

As mentioned in chapter 5, KCCC used to have nutritional support programmes, funded by USAID and WFP. The USAID funding was channelled through the US organisation ACDI/VOCA in a grant, which expired in 2006. When Ediofe Health Centre first began HIV/AIDS activities in 2004, it included food supplements for people living with HIV/AIDS. But when the time came to reapply for funding in 2005, general food support was not included. But up to today, they have a limited food programme supporting the most vulnerable people living with HIV/AIDS, and vulnerable infants.

¹⁰⁷ He holds a diploma in business administration and accounting, and previously worked in the Ministry of Finance and Kampala City Council.

¹⁰⁸ He was trained as a community health worker by KCCC around 1989, and afterwards volunteered in his local community, educating about sanitation and hygiene issues.

The clients, who the Ediofe community counsellors visit, are all clients in Arua Hospital's AIDS programme (AHAP). Arua Hospital is a government, regional referral hospital, whose AIDS programme is largely funded by MSF. In AHAP, nutritional support was also previously part of the antiretroviral therapeutic package: every client who started ARV treatment, received food support for the first 9 months. When the 9 months elapsed, the clients were given hoes and seeds to help them start cultivating their land again. This programme, which was supported by WFP, was discontinued in April 2008. What remains in Arua Hospital is a more limited programme offering 'therapeutic nutritional support' only for the weakest clients¹⁰⁹ (Fieldnotes 29 May 2008).

How food support became 'unsustainable'

The discontinuation of food support in connection with AIDS treatment & care programmes from 2006 to 2008 appears to be a general phenomenon in Uganda, except in Northern and North-Eastern districts¹¹⁰. I have not interviewed any representatives from the organisations funding the food support, and the official documents offer few clues about the donors' priorities and the reasons for changing them. But from my experiences in all the three Catholic organisations, plus Arua Hospital, the discontinuation of general food support to people with HIV/AIDS was a reality, which to most programme coordinators seemed impossible to affect. On my first visit to KCCC, the fundraising coordinator explained that WFP's discontinued food support had resulted in poorer adherence rates among their clients. I asked him if there are not any donors willing to food support these days, and he replied 'no, do you know any?' (Fieldnotes 1 Apr 2008).

I will suggest two possible explanations for the changes in the donor's priorities. First, from 2008 there seem to have been new country-specific considerations. In 2008, WFP Uganda adopted a new country strategy, which identified Karamoja (in the northeast) and the post-conflict affected Northern Uganda as the most acute locations of food insecurity in Uganda (WFP 2009: 3-4). With ACDI/VOCA's new grant from USAID for 2006-2011, they are to provide food aid to people with HIV/AIDS *only* in Northern and Eastern parts of Uganda (ADCI/VOCA 2010). Thus it seems that other situations of food insecurity have been prioritised over general

¹⁰⁹ At end of May 2008, the programme had provided therapeutic nutritional support to a cumulative of 500 clients, according to the in-charge of AHAP.

¹¹⁰ See for example, TASO's experience:

http://www.tasouganda.org/index.php?option=com_content&view=article&id=52&Itemid=62 (last accessed 8 Jan 2011).

food support to people living with HIV/AIDS¹¹¹. In this context, the Northern and North-Eastern regions of Uganda may have had greater claims to food emergency during this time, given the post-conflict context in Northern Uganda and persistent problems of floods and droughts in the north-east.

Secondly, we can possibly locate the changes in donor prioritisation of food aid to people with HIV/AIDS in the shift from the ART scale-up being considered a humanitarian emergency to being transformed into a more consolidated long-term intervention. In their study of ‘the sustainability doctrine’, Swidler and Watkins demonstrate how most forms of material help are considered illegitimate in development projects as they are suspected to only produce dependency (Swidler & Watkins 2009: 1184-5). In contrast, in humanitarian assistance food relief is one of the central methods of ‘saving lives’ in times of conflicts and natural disasters (e.g de Waal 2007). The scale-up of ARV treatment in itself is a possible central factor for the shift. With the access to ARV treatment steadily increasing, donors and implementing organisations find themselves providing treatment and care to a growing number of clients, who at the same time possibly live longer and in a healthier state. In that context, continuing to provide food support can produce an experience of endless demand. If it is not possible to develop manageable criteria that sort out which clients are eligible for food support and for how long, it might be easier to discontinue the programme all together.

Among the programme coordinators, counsellors and community workers in the three Catholic organisations, there were divergent views about the discontinued food support programmes. In the following sections, I analyse the different sides of this debate.

But the drugs do not work without food

A number of counsellors and community workers in the three Catholic organisations were critical of the discontinued food support. It is significant to notice that their criticism was primarily connected to ensuring ARV treatment success and not so much a general appeal for food support to people living with HIV/AIDS.

The KCCC community health worker, Ephrance, who assured me that KCCC ‘only give the clients drugs’, claimed that many clients were not improving while taking ARV treatment or had stopped their treatment, because of lack of food:

¹¹¹ However in other parts of eastern and southern Africa WFP is engaged in a new project called Food By Prescription. Under this policy nutritional support is granted as a therapeutic measure to those meeting specific medical criteria (WFP 2010).

“that’s why people, they remain weak, because of, because of bad feeding . . . you know Kampala here there is no garden, eh when we don’t have money, we can’t have different types of food . . . a big number, they have don’t enough money for feeding them . . . when you are sick it needs you to eat well . . . Then after eating, you take the drug, you recover very fast, but then the problem is money, and some they don’t have a job . . . before, you were working, self-employed, but when you are getting sick, you can’t go to work” (Interview 11 Feb 2009).

As illustrated in chapter 6, in KCCC and the AIDS clinic in Maracha Hospital, one of the rules clients have to follow to ensure treatment efficacy is to have a balanced diet or at least ‘eat something’. However, many of the clients I met on home visits and in counselling sessions were struggling to eat well. The challenge is not only one of general poverty, but also the fact that HIV-related illness in both urban and rural settings often leads to diminished household income and/or agricultural productivity (see e.g. Kaler et al 2010; Russel & Seeley 2010; Haddad & Gillespie 2001). There were many stories in KCCC of clients who were afraid to start ARV treatment, because they felt incapable of getting enough to eat. The storekeeper, Miriam, who used to work with food distribution said: “And at times, now these days, there are some clients they are just fearing to be on what, on the drugs, now they are telling me, if you take the drugs now . . . there’s nothing to eat, how am I going to survive? Ah I’m not going to take the drugs” (Focus group discussion 16 June 2008).

The clients served by the community counsellors from Ediofe Health Centre’s programme used to access food support in Arua Hospital. Some of these community counsellors also found the discontinuation of food support to have affected how well their clients were able to recover. Mathias Anyoku for example said:

“the World Food Programme used to give us food, which was a substitute, it made our lives comfortable ... it’s one of the difficulties we counsellors now have, because that time, these people could get substitute food...which would make them recover greatly from the difficulties, poverty and the rest of it, but now that thing is no longer there, so that one is almost breaking, almost affecting our job” (Interview 1 May 2009).

The Arua DFP also regretted the discontinued food support. He argued that the lack of nutritional support for people receiving ARV treatment was one the biggest challenges in the diocese, but “the diocese doesn’t have capacity to do it, most donors these days unfortunately do not support nutritional or food distribution to clients, and that is an aspect which is really very necessary in the community, somebody on ARVs needs the food to give the strength of the drugs to work” (Interview 31 May 2008).

Such statements from community workers and programme managers point towards the rationale mentioned above; that people living with HIV/AIDS

require services specifically tailored to their needs to help them survive and recover. The previous provision of food support can be seen to have produced the notion that ‘therapeutic citizenship’ comes with an entitlement to access food support together with the ARV treatment. Among the Ediofe community counsellors, such a notion was reflected in Matthias’ evaluation of the changed situation for clients in Arua Hospital:

“He’s not getting that type of help, we got during our time, he’s not getting, it looks a little bit of discrimination, they feel but you people, you were better, we are disliked, that’s . . . the feeling they have” (Interview 1 May 2009).

Another Ediofe community counsellor, Sharon Atiba explained that her clients had expected that registering as a client would entail access to food support:

People complain that they are not getting benefits, they are registered. People have been receiving help, these days it’s not there, what has happened? Yeah, it used to be here some time, but it has been cancelled. Some people used to get food from Arua Hospital, it has also been cancelled, so they questioning us as community counsellors, what happened? (Non-recorded interview w. translation 30 Apr 2009).

There is a sense of injustice and discrimination in the clients’ disappointments of being left out of the benefits that others before them received. The clients appear to question the community counsellors from the position of equal entitlements as therapeutic citizens. However, as I will return to later, the way some clients and community workers attempted to address the discontinued food support may pose questions about the notion of therapeutic citizenship.

Food support has created a demanding attitude

While some community workers and counsellors subscribed to the rationale that people living with HIV/AIDS should be entitled to food support, there were others, who problematised the notion of entitlement to special services. On one of my first visits to Ediofe Health Centre, Jimmy Ariko, the coordinator of the home-based care programme, told me about the limited food support programme they have at the health centre. The topic shifted to the discontinued food support in Arua Hospital. Jimmy said that now that this food programme had been stopped, some even refuse to take the drugs. The problem is:

‘our clients want support. If you tell them about how to do income-generating activities, they receive it with mixed feelings. MSF stopping the food is a big problem, because people have been relying on that food, and they feel “I’m sick, I should be supported”, even though some of them are well enough to work. . . We are trying to impart in people that support is time-limited, so you have to find ways to stand on your own’ (Fieldnotes 7 May 2008).

Jimmy thus problematised the way food support has created a sense of entitlement among their clients, which he finds problematic because it pacifies clients, rather than encouraging them to take responsibility for their nutritional situation. In my interview with him, he expanded on this view;

“ . . . it’s a bit embarrassing, the attitude of some of our clients . . . They are so demanding . . . especially the food, when they are able they should always not be on the side of beggars, they should learn to, to work and earn or, even they dig . . . so that they are self-sustained. So you find that, this area of demanding too much, is . . . demoralising, because you cannot always have something there for somebody who comes, what about you? Where do you get yours?” (Interview 29 May 2008).

Jimmy pointed to a similar dilemma as they had experienced in KCCC: in contexts of scarcity, people who are not living with HIV/AIDS are also struggling to put food on the table. Why should clients be entitled to receive all these free things, when we are all looking for what to eat? In this context, the clients’ insistence that they should be supported because they are sick was demoralising to Jimmy.

In chapter 5, I mentioned that in Maracha Hospital the medical director Dr. Austin and the community coordinator Jeremiah regretted that the hospital did not have resources to provide nutritional support, because such support should ideally be part of an ARV treatment programme. However, Jeremiah also pointed to dilemmas with providing food support:

“you can’t provide people food because they are sick for life, that is not possible, food for these people, they must be trained, they have relatives, they must be empowered, to grow them food. Rather than to say every time, oh we are providing ARVs, here we need food here, this creates more of syndrome looking for treatment places” (Interview 22 May 2009).

Jeremiah’s statement point to the changed context of ARV treatment in comparison to for example KCCC’s early days; people are now sick for life and therefore if you provide food for these people you may instil a demanding, passive attitude among them. Instead, he argues, they and their families must be empowered and trained to ensure they take responsibility for their nutritional situation.

In KCCC, some informants also found that the previous food support had created a demanding attitude among their clients. During a pre-test counselling session with a young woman, Jagwe explained some of the rules of ARV treatment, including ‘avoiding worry’. This prompted the young woman to ask: ‘How can you avoid worry if you don’t have money, have nothing to feed on? What advice do you give?’ To this Jagwe replied:

I say, this organisation helps in treatment. Then you can also try to find work and get money. The organisation cannot give everything, at least they provide all the

treatment. When you get better, you can start looking for a job. It's good to be creative. There was a programme here that gave food for 5 years. People ate that food! Up to now, they still ask about the food. Stop this thing of thinking, we're going to give you, to give you. In Luganda we say, you can't give me a goat and you give me a rope as well (Fieldnotes 17 Dec 2008).

Like Jimmy and Jeremiah, Jagwe problematised how the food support had made clients passive, just 'waiting to be given'. The clients just relied on the food support, instead of being creative and looking for income-earning opportunities.

Some informants additionally problematised how granting entitlements on the basis of HIV positive status, could make it desirable to test HIV positive. A young woman, who was a peer educator in the HIV/AIDS sensitisation project run by Arua Diocese told me about a woman who kept going for HIV testing in various health centres, even though she kept testing negative. Eventually the woman went to Arua Hospital, where she also tested negative, and then she started to cry. The peer educator reckoned that the woman had been interested in accessing the food support (Fieldnotes 30 May 2008). In Eastern Uganda, Whyte et al. heard similar stories of clients who were hoping for a positive test result in order to qualify for various support, as well as of 'clever' clients who accessed medicine and food from several programmes or clients who had falsely obtained cards showing they were HIV positive (Whyte et al. 2010: 91).

Who deserves to eat?

Another problematisation of food support for people living with HIV/AIDS, which has become relevant in the context of the ARV treatment scale-up, is that now there are simply too many clients to support everyone. With so many clients, how will it then be possible to decide who will get the support and who will not? During the preliminary feedback meeting with the home visiting team in KCCC, I asked them what they thought of the clients 'complaining' about the discontinued food support and if they thought the programme ought to be re-introduced. Below are excerpts of this debate:

Anna: The thing of food that is why some people don't adhere, because they fear taking the drugs. But the problem is now that there are so many, not everyone would be able to benefit. Those who don't benefit will feel discriminated.

Matilda: Giving them food would be good, but the problem is that there are so many now. When people start treatment, they may be very weak, and they have lost their job, and there are very few jobs here, so it's difficult to get a new job. But if they get a loan it will also be difficult for them to use it for business, they may get a loan and use it for food. So having that programme would be good.

Mr. Bisase: We need to have a food programme that doesn't hurt other people. Everyone wants to eat. Surely others are badly off, how shall we decide who gets

food? That criteria has to be worked out carefully. Then sustainability, as she said few organisations are doing it now. If we get food, it should cover everybody. For sure, food support is still needed (Fieldnotes 21 Jan 2009).

As this discussion indicates, the community workers found that reintroducing the food programme would be good, because their clients often struggle to get enough to eat and therefore do not adhere well to the treatment. But many of the community workers also pointed to the increasing number of clients as a challenge. As the coordinator Mr. Bisase, argued, if the food programme was to be reintroduced it would have to cover everybody, because they cannot make the decision of who deserves food and who does not - that would be discriminatory. But Mr. Bisase found that in the face of limited donor support to food programmes, reintroducing the programme in such a way seemed unrealistic.

However, in KCCC and the other organisations, they are in fact already involved in deciding who deserves food support and who does not. As mentioned at the start of this section, in KCCC, Ediofe Health Centre and Arua Hospital some kind of 'emergency' or 'therapeutic' food support remains. Now with more limited supplies, it is up to the organisations to decide who 'really needs' food support. The dilemma of deciding who is entitled to food support is parallel to the forms of social triage, which emerged in the context of limited access to ARV treatment prior to the ARV scale up (Nguyen 2005; Whyte et al. 2004). Whereas groups of people living with HIV/AIDS in Burkina Faso favoured the 'dynamic' members (Nguyen 2005: 132), families in Uganda had to make painful decisions about who to buy the expensive treatment for, or what other life projects would have to be prioritised over securing ARV treatment for one person. Sometimes the decisions were structured by expectations of who would be a 'responsible' patient (Whyte et al. 2004: 20-1). With emergency food, however, the task for the organisations is to decide who is 'really suffering', and not just begging for assistance.

KCCC uses some of their own funds to provide emergency food for the most vulnerable clients, and to those clients staying in 'the patient's home' (Fieldnotes 1 Apr 2008). Christine explained:

"when we reach in a home that we find patients they really need food, they don't have a anywhere to get food, so those ones are the ones we provide with food; that we don't give to everybody, that is our patients that they have to get food. We select and find that this is really a person who is really needing food so we, that we must give." (Interview 21 Apr 2008).

The criteria for accessing emergency food were not openly discussed among counsellors and community workers, or clearly communicated to clients. Sometimes, when clients asked if they could access food support, the counsellors and community workers replied that the food is only given

to a few, 'deserving' ones. For example when a client asked 'how can I get assistance in form of porridge', the counsellor replied 'Assistance is basically given to young children and very old people' (Assistant notes 11 June 2008). Other times, the counsellors and community workers responded to such requests with the explanation that the donor had stopped funding the food programme.

Ediofe Health Centre's limited nutritional support programme provides powdered milk, sugar and rice to people living with HIV/AIDS and vulnerable infants¹¹² for a limited period of time. According to Jimmy, it is the clinical officer in the health centre who has the mandate to decide who needs food: 'your physical appearance will show whether you need assistance or can sustain yourself' (Fieldnotes 7 May 2008). In May 2008, there were about 35 people accessing this food support, and according to Jimmy, these people were the really weak ones 'who are suffering'. Those who, however, are deemed capable of being able to sustain themselves cannot access this food support (Interview 29 May 2008).

On one of the few home visits in participated in the Ediofe programme, I experienced that a client was referred to access this food support. The client was an elderly woman living with her children by the trading centre in Ediofe. Her oldest daughter was the one caring for her. The woman was taking TB treatment and had been given a protein paste as a food supplement at Arua Hospital. When she complained of having problems paying rent and buying food, when she also had to take care of her children, the community counsellor and Jimmy encouraged her to go to Ediofe Health Centre to get 'the small support' of food supplements for a few months. They made clear to her that the support would not be much and that it would be time limited (Fieldnotes 18 March 2009).

From passive recipients to active, responsible therapeutic citizens

The above sections have illustrated how, in the three Catholic organisations, the rights of people living with HIV/AIDS to social services and food support are debated with reference to sustainability rationalities, as well as a kind of holistic care rationality orientated towards treatment efficacy. Most of the employees recognise that food insecurity and social problems pose challenges to the ability of clients to follow 'the rules' of ARV treatment and Positive Living, but in most situations they face considerable limitations in addressing these challenges. Moreover, as the food debate illustrates, there is also a widespread perception that the organisations should not provide such assistance. In line with neo-liberal

¹¹² Such as orphans, twins and children of people living with HIV/AIDS.

development rationalities, some employees are concerned that the provision of social services, especially food aid, will only produce passive clients, rather than active, responsible clients who will come out of the situation better equipped to take care of themselves and their families. In the following sections, I analyse how there is a dominant emphasis on educating and counselling clients to take responsibility for their own social situation, in all the three Catholic organisations. I begin with KCCC where the debate, among some counsellors, is orientated towards their ideals of holistic care.

KCCC: ‘you have been given the drugs for free so at least you can work for yourself’

In KCCC some employees framed the client’s struggles with social issues as a dilemma between rationalities of holistic care and sustainability. This was most explicitly in Damian’s case. Compared to KCCC’s earlier holistic care commitments, Damian identified a change in the way social support services were no longer considered sustainable in the new context of ARV treatment availability. Talking about clients who were looking in vain for jobs or struggling to pay school fees for their children, he said “much as I am trying to counsel this person to get better, but some other social needs are not addressed” (Interview 28 Apr 2008). Explaining how KCCC came up with the idea of holistic care in response to the social needs of people living with HIV/AIDS, he said:

“That when HIV and AIDS, it is multi-sectoral, it is holistic, you have to deal with total personality, and you are not going to give drugs only and think that the person will improve. There is food, there is rent, but the question is: are they sustainable? Like we used to pay for house rent, but we couldn’t sustain it. And years went by and we started now refraining ourselves from paying house rent. Because now after getting ARVs, our patients are getting better. And why do we want them to get better? It is they look for what they can do. They have to sustain themselves. But those earlier days, people were thrown out of the houses; you find them on the church compound” (Interview 28 Apr 2008).

Apart from the fact that KCCC realised that interventions like paying house rent for the clients were not sustainable in the long run, Damian also points to the fact that the access to ARV treatment has changed how they are caring for people living with HIV/AIDS. Today, their clients have the opportunity to improve in a way, which can allow them to return to providing for themselves. The possibilities ARV treatment brings for ‘bringing people back to life’ comes across as a crucial context for the changes in KCCC’s holistic care provision. Unlike in the early days, where biomedicine offered little hope of significantly restoring the clients’ health, today there must be an emphasis on how to enable clients to return to being self-sustaining.

Despite the possibilities of returning to productive life with ARV treatment, the experiences of many of the counsellors were like Damian's; that their counselling was not 'working', because of social needs, which they could not address. One counsellor, Daniel talked about how clients kept asking questions, which they as counsellors were not in a position to answer, such as "I don't have what to eat, I don't have money to pay rent, I have no work, my kids are not going to school, counsellor what do I do?" To help clients address such needs, Daniel felt that the most important thing counsellors could provide was information, because "other aspects are not kind of sustainable . . . we gave food as an institution . . .but we can't say we keep giving food" (Interview 3 Feb 2009). In line with neo-liberal development rationalities, what Daniel proposes as a sustainable solution is to 'empower' clients with information to help them find ways of helping themselves out of such problems. Another counsellor, Rose, similarly, identified 'needy clients' as one of their main challenges:

"the majority of them are needy, and they are so demanding from us, they think we have, yet what we have is just the service that we have, they ask you, we hear of KCCC offers school fees, my children do not go to school, they ask we don't have food, yet we don't have food either to give them" (Interview 27 Jan 2009).

Apart from frustration, what Rose's statement reflects is a similar problematisation of the client's 'begging attitudes' as Jimmy from Ediofe Health Centre was engaging in. The word *demanding* makes it seem like the clients' appeals for assistance are not legitimate. A similar framing of appeals to help with following 'the rules' as an illegitimate form of begging was also evident in Jagwe's counselling session with the young woman mentioned above. The advice he gave to her was that if she wants to do well on ARV treatment, she has to be creative and look for a job instead of just waiting for assistance to be given to her. So not only is the provision of food support and social support unsustainable, it may also be detrimental in its creation of passive clients.

In an informal conversation with the home visiting coordinator, Mr. Bisase, he argued precisely that urging clients to take responsibility to 'work for themselves' is the only solution to the client's social challenges, because other forms of assistance, especially food support only creates dependency. He explained that when the food programme was being phased out, the intermediary NGO that channels PEPFAR funding to KCCC, started a programme training the clients to build small 'gardens', where they grow vegetables and fruits in used jelly cans. However, the programme worked only for a few months. He said 'but there is also that dependency syndrome, waiting to be given. We tell them: it's high time, you start supporting yourself, you have been given the medicine for free, so at least you can also work for yourself. You see we found that food support was

not sustainable' (Informal comm. 19 Dec 2008). To Mr. Bisase the failed urban garden project only illustrates how the food support has produced a 'dependency syndrome' among the clients. As a response, clients are told: now that the donors have made the extremely expensive ARV medicine available to you for free to help you prolong your life, you could at least take responsibility to find ways of supporting yourself; you cannot rely on the donors for everything.

So, in the language of 'rights and responsibilities' of people living with HIV/AIDS, the premise that these employees outline is that in accessing the right to free ARV treatment, you have the obligation to address with your own means (or through social relations) any social barriers to treatment success. In other words, it is your own responsibility to see that you follow the rules of ARVs: eating well, not worrying, not overworking, adhering to the treatment, coming for your appointments etc. As a contrast to 'the sick', the volunteers were caring for in the early days, there is here a shift from the passive sufferer towards the active, responsible therapeutic citizen.

But we assist with psycho-social problems

When counselling and information are the main methods to help clients overcome social problems that may act as barriers to treatment efficacy, such problems tend to be termed 'psycho-social'. Psycho-social problems may include things like 'lack of rent, no school fees and domestic violence' as Mr. Bisase explained when introducing a new form to be filled by the community workers when they go on home visits (Fieldnotes 5 Jan 2009). The term psycho-social is widespread in the AIDS field. In the context of AIDS treatment, it reflects the rationale that problems that cause clients to worry or lose hope can have negative implications on their determination to prolong life and more importantly practically decrease their CD4 counts (recall that worrying is one of the 'great enemies of the CD4'). Psycho-social problems thus pose a threat to the project of saving lives with ARV treatment.

In KCCC, the widespread use of the term reflects the transformation of their rationalities around holistic care. Whereas they earlier attempted to help clients by paying their school fees, paying their house rent, getting them something to eat or providing them with capital to start a small business, they now *counsel* clients on how to overcome such problems. Counselling constitutes these social problems as belonging to a psychological and emotional realm rather than a socio-economic realm; hence they are 'psycho-social'. In my first meeting with the home visiting team to discuss my fieldwork, the community health worker Joy explained what they do as community health workers. After some time, Mr. Bisase,

interrupted and said: ‘we also counsel on psycho-social aspects, you know no income causes worry’. Giving an example of such counselling, he said, we ask them: ‘Can’t you do something to make some money before just receiving?’ (Fieldnotes 12 Dec 2008). Mr. Bisase’s example reflects the fact that defining these problems as ‘psycho-social’ means locating the problem in the clients’ self-perceptions; the clients must work on *how they relate* to problems like having no income and not being able to pay school fees. As Anthony said, what they, as counsellors, could do to help clients with their social needs was to “use our skills to help them, to have a change in their lives, and to make an informed decision about their problems” (Interview 2 Feb 2009).

Ediofe Health Centre’s HBC programme: ‘the client belongs to the community’

As mentioned in chapter 5, the coordinator of Ediofe Health Centre’s home-based care programme, Jimmy Ariko, explained that the rationale of the programme was to render the family and the community responsible for addressing the multifaceted needs of people living with HIV/AIDS. This he framed as ‘the client belongs to the community’. From the onset, the idea with Ediofe’s HBC programme was thus in line with neo-liberal development rationalities on empowering families and communities to find ways of supporting people with HIV/AIDS in ways that are not dependent on donor funding. The fact that Jimmy found the ‘begging attitudes’ of clients demoralising can thus be linked to how begging for assistance is indicative of a client and a family not taking on the responsibility to manage the rules of ARV treatment. The quote below illustrates how he found that lack of food was not a valid excuse for poor treatment adherence:

The other thing which has not been going well down there is, either I don’t know how to explain it, you know these ARVs are expensive drugs and eh, they are not really to be wasted, but you find a patient, who is given these drugs and does not take them, the community counsellor goes to visit and finds these drugs there in the corner, . . . And this drug is for the well-being of you, the patient, you find they don’t take these drugs, why don’t you take? That there is no food to eat, because the drug causes a lot of hunger and so on, so I think that would mean counselling the family members to monitor the taking of the drugs (Interview 29 May 2008).

Like Mr. Bisase in KCCC, Jimmy positioned the clients’ responsibility to follow the rules well with the donation of the expensive ARV medicine. ‘Now that the donors so kindly have given you the drugs, which are for your own well-being, you could at least take some responsibility yourself’. The solution to irresponsible clients that Jimmy proposes is like in KCCC more counselling and education, but here not so much of the individual client as of the family.

Whereas some of Ediofe's community counsellors, such as Mathias, were quite critical of the discontinued food support, Sharon emphasised to me that she had to encourage clients to work for themselves. I previously referred to how she had experienced that clients kept asking her what had happened to the food support. I asked her how she replied to these questions. She said:

'About food, what I tell them is the food was given to those who were completely bedridden, those who are sick, it used not to be given to everyone who is positive. I also encourage them to keep working, it's not the working, which makes them sick, as long as they're able they should work and grow food for themselves'
(Non-recorded interview w. translation 30 Apr 2009).

Thus apart from urging clients to take responsibility for their own livelihoods, Sharon also tries to challenge the notion that being HIV positive implies an entitlement to food support. She claims that the food support in Arua Hospital was never given to everyone who is positive. Yet in the previous WFP-supported programme, it was in fact given to everyone starting ARV treatment.

As in KCCC, some of the community counsellors in Ediofe framed their primary responsibility in the 'psycho-social' realm. Josephine identified her role in the following way: "as a community counsellor, I have to help those suffering on this HIV/AIDS, not giving them money or food or something like that. You just help them to just forget about their psychological torture and so on" (Interview 17 May 2009). Josephine's statement reflects a negotiation with what is legitimate for counsellors to provide, which is certainly not money or food.

Maracha Hospital: 'providing ARV treatment is a problem, not a solution'

In chapter 5, I briefly outlined how Maracha Hospital's management found that 'additional' services such as nutritional support and home-based care were needed to make the provision of ARV treatment successful, but that the hospital was currently not in a position to offer such services. In this section, I discuss the AIDS clinic in Maracha Hospital in a bit more detail than the two other organisations. The challenges of this clinic vividly illustrates the dilemmas of providing ARV treatment in 'resource-limited' settings, and how working on client's socio-economic responsibility seems a logical response under such circumstances.

Dr. Austin located their challenges with running the AIDS clinic to their lack of outside funding to cover salaries and fund 'other activities' like

home-based care¹¹³. He contrasted Maracha Hospital with Arua Hospital who receives funding from MSF and Kuluva Hospital¹¹⁴ who receives funding from Inter-Religious Council of Uganda. He and Jeremiah explained that the hospital was experiencing a higher demand for their services, while the government's Primary Health Care grants were not increasing. Because the hospital was not willing to raise the user fees anymore (cf. their commitment to be accessible to the less privileged), they recently had to reduce the number of the staff, which as mentioned meant that the AIDS clinic was left with only one permanent employee. The hospital staff is also paid less than in government facilities (Interview 22 May 2009). This is actually quite common in mission health facilities in Uganda (Barugahara et al. 2008). Without outside funding, the AIDS clinic mostly constitutes an added expense for the hospital. The recently introduced user fee helps them recover some of the costs of running the clinic. But it is noticeable that this user fee is only half of what is paid elsewhere in the hospital (Interview 22 May 2009).

The only way the clinic has been able to continue after the staff reduction is actually because of the intern/volunteers who have hanged on after their internship. Jeremiah said that they had been asked to volunteer, but it was clarified that they would not be employed, but only receive some allowances when they go on outreaches (Interview 22 May 2009). When they went on testing outreaches, which they did three to four times in a month, they received 8,000 shillings for transport and lunch¹¹⁵. The interns were extremely dissatisfied with the situation, but they still continued to work in the clinic in the hope that other opportunities would come their way one day, where their experiences in HIV/AIDS counselling would be useful. However their attendance was not always regular as they were at times looking for other sources of income (Interviews 28 Apr; 12 May 2009).

In this context of extremely limited resources, a notion of special entitlements for people living with HIV/AIDS may seem even more problematic than in KCCC. Jeremiah said:

" . . . another challenge there is . . . demand is high, but care, care may be less . . . yes, people need the services, but because of inadequate staff and so on, care may

¹¹³ The only outside funding the AIDS clinic receives is the ARV drugs, septrin and testing kits provided by the government (through the Ministry of Health). The clinic also receives some funding from AIC for additional testing kits, to cover the gaps in the government supply. And occasionally, MSF fills gaps in the government's provision of ARV medicine.

¹¹⁴ An Anglican hospital, 7 km. south of Arua.

¹¹⁵ Given the fact that this was the only pay the interns received, they rarely used this money for transport and lunch on the testing outreaches.

be compromised..., and then . . . the clients actually demand, eh how do I put it, ok they expect that everything for them must now be free of charge, they must get free things, including food, so you cannot provide that. Yes, you cannot meet this need” (Interview 22 May 2009).

The hospital used to have some funding for ‘community activities’, which included home visiting and HIV/AIDS sensitisations conducted by the post-test club¹¹⁶. But now that this funding has come to an end, these activities have more or less seized¹¹⁷. The hospital attempted to continue with home visiting by using some of the money from the government PHC grant for it. But as Dr. Austin explained to me, these grants come irregularly, and ‘when these people had moved for two months and were not paid, it died out’ (informal comm. 25 Feb 2009). Jeremiah explained that they could not continue with home-based care without outside funding, because it is a very expensive intervention:

“actually, we used to follow these clients, first for adherence of ARVs, two also to give them some psycho-social support at home and then encouraging them on raising their own funds that income-generating activities, which they can do, but it’s now not possible for the hospital to do this home-based care, because there are no funds, it requires intensive funding, you have to make fuel, you have to buy some. . . home-based care kits and so on, it’s very expensive. So as a hospital we could not . . . only staff goes to see the nearest ones” (Interview 22 May 2009).

Whenever I discussed the matter with Joyce, she insisted that they still went on home visits every Wednesday. However, it was also clear that she was the only one left to do the home visiting, and as she said ‘if we are near, we can foot, if they are far, we ask for a vehicle. But sometimes it is not available’ (informal comm. 24 Apr 2009). In the interview she maintained that they manage to go to ‘far places’ with a vehicle once or twice a month (Interview 12 May 2009). Thus, home visiting was dependent on Joyce having the time and energy to walk to some nearby clients and on a sporadic availability of transport. With the help of my car, I went with Joyce on home visits three times over a period of two months.

On these home visits, there was a greater emphasis on relationship and family issues than in her consultations in clinic. As detailed in chapter 6, Joyce’s counselling-consultations are brief sessions which mostly consist of generalised ‘treatment instructions’ with limited room for individualising, introspective explorations. Taking together with limited home visiting, this means that in the AIDS clinic in Maracha Hospital there is not much focus on ‘psycho-social’ problems; of inserting social problems into a psychological and emotional realm. In the clinic, the

¹¹⁶ These activities have been supported by AIC, PSI and the USAID-supported Uganda Programme for Human and Holistic Development (Uphold) project.

¹¹⁷ The post-test club also collapsed because the chairman misappropriated the funds.

disciplining tone of Joyce's treatment instructions left an impression of clients entirely left to their own devices in terms of overcoming any hurdles to follow the rules of ARVs. Below is an example from one consultation with a client, which illustrates how Joyce attempts to make clients take all responsibility for following 'the rules' in the context of the clinic's minimal services. The client was a woman on septrin, who had missed her appointment by four months.

Joyce: *I told you not to miss this drug, you stopped way back in November. Why did you miss?*

Client: *There are a lot of problems at home, I have no money. I don't know how to get money, there's no one to help me get money, that's why I missed.*

Joyce: *Have you got the money now to enable you to come here?*

Client: *I did not get that info (until recently) that once you don't have money you leave your book here, that's why I have missed all these days.*

Joyce: *If you take the drug today, then you miss tomorrow, will it help you?*

Client: *Because I have no money, sometimes I can go for casual work for 1,000. I use that money to buy food. Somebody has helped me today with 1,000, that's why I decided to come.*

Joyce: *I know your problem is not money, maybe it's another problem. Even when the drugs were given free, I noticed you were missing the drugs also. If I check your previous books, I'll find you missed, one month you get the drugs, one month you missed. Is it not true? . . . Somebody has just given you money today, now will you manage to come the other day, when you don't have money? I learn that you sold a goat last week, what did you do with that money?*

Client: *I am desperate in terms of food, I have children, I used that money for buying food.*

Joyce: *When you used to come for the drugs, you were healthy, but you stopped in November. That's why your weight has become low. That's why there are many diseases coming in. If there's no money, you come and I give you drug. You see all these books, these are people who don't have money, but I'm giving them drugs (Fieldnotes 17 March 2009).*

Towards the end of the consultation, Joyce said to me and Jimmy in English: 'poverty is there, but she's just not serious with her life, she used to take the drugs, did everything. But 4 months is just too long'. Thereafter, Joyce directed the client to go and see the doctor, and when giving her the little paper bag of septrin pills, she said: 'Today I'm giving you this drug, I've learnt that you take alcohol, that is bad with this drug. You should become healthy and don't miss this drug' (Fieldnotes 17 March 2009). This interaction illustrates that to Joyce poverty and being 'desperate in terms of food' are not valid excuses for missing appointments (plus it may be an excuse to cover up having 'misbehaved'). Even when apparently faced

with severe poverty, Joyce urges the client to be ‘serious’ with her life and follow the rules of this treatment.

The interaction also illustrates how the combination of limited follow-up in clients’ homes, the introduction of user fee, and food insecurity (usually leading to deteriorated health) can result in clients’ missing out on treatment, when they do not have the required fee to come for their appointment. Joyce kept repeating to the clients that they should come for their appointment even if they did not have money for the fee, but it seems many clients continued to be afraid of coming when they did not have enough money. Since the clinic’s possibilities of following up clients in their homes is quite limited and sporadic, as a matter of survival it thus becomes the clients’ own responsibility to always come to the clinic when they fall ill (before they are so ill that they become bedridden) and/or to rely on relatives or other social networks to provide transport to the clinic.

As a result of the hospital’s limited access to resources that could enable them to provide more comprehensive treatment and care services, Dr. Austin and Jeremiah wondered whether it actually made sense for them to have an AIDS clinic:

Jeremiah: “in fact we could even do without the HIV clinic, because the package we’re supposed to provide for the people, so if we can’t do it, providing HIV care is very expensive and if you don’t have additional support, that means you’re failing. You cannot continue to recruit people on ARVs, when you cannot follow all of them, this is unethical, yes, so . . . Facilities who have support like Kuluva, Arua Hospital, they are able to provide comprehensive care and have adequate. But here for us, we don’t have any...” (Interview 22 May 2009).

Later in the interview, when we were discussing the lack of nutritional support, Jeremiah concluded that in “a resource limited place like this, providing ARV is really a problem, it’s not a solution, it’s a problem” (Interview 22 May 2009).

Praying to God and begging for mercy

The previous section has illustrated how there is a dominant self-responsibilisation discourse in the three Catholic organisations, which posits that clients must take responsibility for their own social situation. But in the three organisations, there was also another type of response to ‘the social issues’ of ARV treatment. In KCCC, some counsellors and community workers banked on KCCC’s pastoral care tradition and encouraged clients to put their faith in God to ‘provide’. In all the organisations, there was a curious parallel between how counsellors, community workers and clients prayed for the mercy of God and how they begged for the mercy of the donors to reintroduce food support. In this

section, I consider first the pastoral approach in KCCC and then the more general point about begging donors for mercy.

KCCC: Have faith in God as your provider

In KCCC, another resort to address clients' social needs was found in the organisation's tradition of pastoral care. Anthony, who has also worked in the Child Welfare department, talked about a pastoral approach to handling 'needy clients':

"people come maybe to the social worker office, say my children are not going to school, I don't have something to eat, I don't have beddings, they come with that idea that this office is responsible for providing, you are supposed to give us these things, these things are here for us [other participants laugh in agreement], but there are so many situations, when they come when there is nothing . . . Yeah, but me as a pastoral counsellor, I sit with this person, I know, I have heard about your needs . . . but do you know, look at God as the provider, let us lift these problems up to God, and we believe that God will provide" (Focus group discussion 16 June 2008).

In this statement urging clients to 'lift up their problems to God' and having faith that with prayer they will overcome their problems, comes across as a method of handling 'demanding clients'. But Anthony was in fact quite optimistic that when they pray to God for help, and lift the client's problem up to God, the prayers are sometimes heard. He said:

"but eventually, even before we provide from our own office, you meet that client and say 'counsellor, praise God, you prayed with me last time, and we discussed, but when I went to this organisation, I got someone who sponsored my child'" (Focus group discussion 16 June 2008).

The close relationship between spiritual and material assistance, which was characteristic of KCCC's early efforts was thus a continuing theme, even if the way they can help with material needs have changed. On one home visit, a close connection between material and spiritual assistance was significant both for the client and for the approach the community workers used. I was going with Matilda Nakya on home visits, and Beatrice Asiimwe had decided to come along. We visited a couple living in the police barracks in Naguru. Only the wife was present during the visit, since the husband had gone to the village.

Matilda and the client had a long talk about her husband who had been on treatment since 2002, and how the money had been disappearing from them ever since he fell ill. The client talked about how people rejected them when they fell ill, including her relatives and the police force, which had 'neglected them'. Talking about how the family was struggling to get by, the client said:

'Are you the same God, this one for those who are sick, and for those ones who are ok? He's the one who said, you pray and you'll be given. My husband is born

alone, he's mother is in the village crying, she has called upon you. But God why don't you answer our prayers? Have we not cried out for you?'

This kind of talk continued for a while; the client insisted that there is one God for those who are ok, and another one for those who are sick. The community health workers insisted that God had not left her. Eventually, Beatrice intervened by sharing her own story:

'There is a time I looked for school fees. Both my children sat for P7, I couldn't even boil water, didn't have charcoal. I was giving them diseases, caused more problems . . . when my husband died, the situation was bad. I looked for something to do, but I failed. I said to God, I'll let go, I have nothing to do. But my children passed P7. .. Now, one of my children is going to graduate from university...I used to attend those workshops about sickness. They encouraged me.

One day, they said at St. John's¹¹⁸: those Christians who have children, come and register. They paid for the boy until P7. Even if we get oppressing situations, never leave God. . . Someone told me to go to Kamwokya, when I got there I failed to talk, because I was just crying. KCCC started paying school fees for my children. Do you see how God made a way? St. John's stopped paying. Me, I'm a protestant, but you see how the Catholics helped me?

There are not 2-3 Gods. The one you think doesn't hear you, he hears you. It's just your time has not yet come. He will help you (Fieldnotes 9 Jan 2009).

In this situation, Beatrice used her own story to illustrate that praying to God will eventually pay off; the client just needed to persevere. This approach constitutes a way of ensuring the client that God has not forgotten her even if she is living with HIV/AIDS – a point that the pastoral workers often emphasised. What is noticeable in this interaction and in Anthony's statement above is that the way God may 'make a way for you' is for you to find another NGO or maybe a relative to offer you help, such as sponsoring your child's schooling. The changed situation for KCCC is that whereas they were previously the ones embodying God's presence by providing such help, they can no longer do so. As Damian put it: 'If we say God is the provider, but there's no provision today, tomorrow, so why don't I leave God?' (Fieldnotes 2 Feb 2009).

In terms of the Christian rationalities in KCCC's work we can thus identify a shift from the early years to today. In the early years, they were 'feeding the hungry, giving drinks to the thirsty and visiting the sick'. They were practically *giving* material things and their time aiming to act as a physical presence of God. Today, they can offer 'only' prayers, consolation and counselling to help clients have faith and determination to find ways of overcoming their struggles. In accordance with sustainability rationalities, provision of the kind of material assistance they once did has in fact become somewhat illegitimate.

¹¹⁸ St. John's is the Anglican Church in Kamwokya.

Giving something small

Yet the idea of what it means to provide care as a Christian was not always easily reconciled with this rationale. Both the counsellors and community workers in KCCC were instructed not to give the clients money or food, and they were also not allowed to accept any form of ‘appreciation’ from the clients. On home visits, community workers were not even allowed to accept tea. Apart from the fact that such professional guidelines go against local norms of reciprocity and of how to treat visitors, Anthony also found that as a Christian you sometimes had to overstep these professional guidelines:

“counsellors are not supposed to give a hand out, but some situations when someone shares with you and you find you may have the tears and you may be forced to go in your own pocket and say if I have 2,000, let me at least offer 1,000, but practically in training, they don’t encourage us to give . . . but in some situations because you believe in God, you go an extra mile . . . God has given me, let me also give, someone might share with me that I didn’t have supper, and you say, in counselling training, they told us not to give, but what does God say? If I really have 5,000, why don’t I offer 1,000, so privately we offer” (Interview 2 Feb 2009).

Among the Ediofe community counsellors, there were similar negotiations around whether it was appropriate to give ‘something small’. Despite the fact that Jimmy complained about the begging attitudes of clients, on the home visits I went on with him, he always made sure to give the clients a little money. And, though he did not say this to me, it soon became apparent that he almost always chose clients for me to visit, who were going to receive a home-based care kit¹¹⁹. I suppose so that the clients would not be disappointed that the *mun-do* (white person) had come with nothing. The community counsellors, Josephine also sometimes gave her clients ‘something small’:

“sometimes when you go for home visiting and you have a lot of money, you can just take to that person, sometimes even things like food items . . . but right now ah-ah, things are really very hard, we just go and visit people just very dry like that (laughing) . . . they also understand . . .

Louise: *Alright, but otherwise you usually come with something small?*

Josephine: *No, if you go, those things, every time, so when the person just sees you like that eh-eh you see my counsellor is coming to me with something that would not be good”* (Interview 17 May 2009).

¹¹⁹ The health centre provided a home-based care kit, which included a mosquito net, bed sheets, a box of gloves, gaze and tape for wounds, a Makintosh rubber sheet (in case the client has diarrhoea) and soap.

Giving something small, whether formulated as Christian giving or as everyday forms of reciprocity, thus had to be carefully negotiated with the concern of creating dependent, passive clients.

Begging for mercy

In the home visit mentioned above, praying to God for help came across as a potentially powerful way for community workers to try to help clients overcome the uncertainty of not being able to follow the rules of ARV treatment and Positive Living well. In fact it may constitute one's only hope since there is little hope in getting any assistance from the treatment programme. Interestingly, some of the community workers referred to the discontinued food support in similar ways. Matilda from KCCC for example said:

“the major challenge is food, most clients have got a problem of food, so I reach there when I have no solution. I try to tell that let us just pray and hope that we will get some people who will start funding that food as we used to . . . but you see that this, this problem will not be cleared, because you see that whenever you go back they will always be asking you that question . . .

Louise: And what do you try to tell them?

Matilda: I normally tell them that we have hope that maybe there is hope that maybe we will get this food once again or we will not get it, I normally encourage them to build this urban planning (Interview 16 Feb 2009).

Apart from encouraging the clients to build urban gardens (growing fruits and vegetables in used jelly cans) and praying to God for help, Matilda also found herself in a situation where she could only pray to God that maybe we ‘we can get this food again’.

The Ediofe community counsellor, Matthias talked about the discontinued food support in a similar way. He talked about how his clients kept asking about the food support, saying: “when will it come, are these people not going to be merciful to us, once more?” Later in the interview, when Matthias argued that the food programme needed to be revived, I contended that it might be difficult because it seemed like the donors had deemed food support unsustainable. To this he said, “that one now, what can you do? There's no way out, so you live at their mercy, you live at their mercy” (Interview 1 May 2009). Although you can argue that I actively encouraged Matthias to reach the conclusion that they are at the mercy of the donors, the notion of begging the donors for mercy was prevalent in my interactions with clients and community workers in other ways.

As I entered into home visits as a representative of ‘the donors’ (despite my insistence that I was only a PhD student), I was continuously met with questions about whether the food support would be reintroduced. For example, on one of my first very home visits in KCCC, the client asked in

the end: 'Is there hope for us to get porridge and oil as we used to get, because that has really affected us. That would help us.' When the client asked this question, the community health worker looked to me to provide an answer. I was a bit speechless, but I replied that I thought it would be difficult because the donors do not seem to want to fund food support to people living with HIV/AIDS anymore (Fieldnotes 12 Dec 2008). In May 2008, I went on one day of home visits with a nurse from Maracha Hospital who has since been 'retrenched'. All the three clients we visited complained about lack of food, explaining that they were too weak to cultivate their land. They asked if I would 'present that complaint' (Fieldnotes 21 May 2008).

Perhaps we can say that these clients were acting as therapeutic citizens claiming entitlement to life on a global world order, to me, a representative from the global North. But maybe it is more appropriate to term this a form of patron-client relation; if you make your case heard to the right powerful people, maybe there is a hope of getting assistance. Because ultimately what clients are taught in all the three organisations is to be grateful for the assistance they do get and should they ask for anything more it might be labelled 'begging'. As Meinert et al. argue being a client in a treatment programme is more about being respectful and grateful, which points to the centrality of hierarchical relations between clients and the treatment programme as patrons (2009: 205).

Chapter conclusion

The previous chapter illustrated how in counselling clients are taught to follow the rules of ARV treatment and Positive Living. But the question of whether 'additional interventions' such as nutritional support, microcredit schemes and school fees support can be provided to help clients to follow these rules is not simple. The kind of 'additional interventions', which may help make ARV treatment provision successful in settings of poverty and food insecurity meet several barriers. First of all, counsellors, community workers and managers have experienced how the previous provision of such services has helped to constitute a notion of entitlement to special support among people living with HIV/AIDS. In the local contexts, the question of such entitlements is discussed against the backdrop of general scarcity. Secondly, it seems that in negotiating with donors and when applying for funding for such additional interventions, the organisations have effectively learnt that the more appropriate solution to the social challenges of ARV treatment success is to enable clients to become self-sustaining.

Consequently, in all the three Catholic organisations there was, in accordance with neo-liberal development rationalities, a great emphasis on

counselling and educating clients to take responsibility for their own social situation. For KCCC, negotiating holistic with neo-liberal development rationalities has resulted in replacing the embodied enactments of 'loving your neighbour' with the consolation of prayers and psychologically orientated techniques of self-transformation.

On a general level, the picture that emerges is that expansion of ARV treatment in Uganda has, rather ironically, resulted in constituting a range of supportive interventions 'unsustainable'. So that currently with the donors' 'generous' provision of free antiretroviral treatment to save lives, the clients, their families and 'communities' must in turn carry the burden of making sure that all the social issues, which may pose a threat to ARV treatment success, are being taken care of.

8. Home visiting and the Ambassadors of Positive Living

Introduction

As mentioned in chapter 5, home visiting is used in many ARV treatment programmes as a method to enable ARV adherence and address ‘psycho-social’ problems. As such, home visiting constitutes a method to enable the clients’ responsible self-government. The method has been inspired by the home-based care initiatives, which were developed in the 1990s in mainline churches across Africa, building on pastoral care practices (as was the case in KCCC). With its emphasis on involving ‘the home’ and ‘the community’, home visiting can be seen as expressive of a kind of holistic care rationality. People living with HIV/AIDS are thus perceived not only as patients in need of medical assistance, but also as members of homes and communities where there may be social, economic, emotional or spiritual barriers to ‘healing’. But as with counselling, the methods and the relevance of addressing ‘the home’ is in the three Catholic organisations today oriented towards bio-political ambitions of saving lives with ARV treatment.

The first part of this chapter analyses the rationales and techniques of the home-based care programme in KCCC and that coordinated by Ediofe Health Centre¹²⁰. I argue that home visiting in these two organisations is a technology of government, which constitutes a means of disciplining and monitoring clients to ensure adherence to ARVs, and which aims to produce responsible and caring families and communities who can and will assist clients’ self-government.

The second part of this chapter considers the common use of HIV positive volunteers to conduct home visits. I argue that these HIV positive volunteers function as Ambassadors of Positive Living. They try to act as living examples in order to encourage their clients to follow ‘the rules’. This part of the chapter begins the explorations of the identities and socialities that are central to the ways people living with HIV/AIDS try to realise the potentials of ARV treatment and Positive Living.

¹²⁰ The home-based care activities in Maracha hospital’s AIDS clinic are not discussed in detail in this chapter, since as mentioned in chapter 7, home-based care was only functioning sporadically.

Involving 'the home' and 'the community'

Before turning to the home visiting practices in KCCC and the Ediofe programme, I outline some general rationales and methods of 'home-based care' in the context of ARV treatment.

In Uganda, practices of 'self medication' and 'home treatment' were previously highly problematised. But for conditions like HIV/AIDS, TB and malaria, various types of home-based care have proliferated in recent years (Grøn et al. 2008: 73; e.g. Ministry of Health 2002). In 2003, the US Centre for Disease Control started a pilot project in Tororo district in Eastern Uganda called the "Home-Based AIDS Care Project" (HBAC). During this initiative, community workers delivered ARV medicine, counselling and medical follow-up to 1,000 HIV positive people in their homes (Meinert et al. 2003; Weidle et al. 2006). The HBAC project served as 'evidence' that home-based care could pave a way for overcoming some of the barriers to ARV treatment success in settings marked by poverty and limited health care infrastructure. Home-based care was seen as promising due to two elements: 'task-shifting' (shifting care tasks from nurses and counsellors to community workers) and overcoming transport barriers to follow-up (Weidle et al. 2006).

The HBAC project also required that clients identify a 'medicine companion' in their home¹²¹. This requirement reflects that the rationale with home-based care is not only to use fewer resources, but also to shift responsibilities for care to other members of the home. As Grøn et al. (2008) argue, the way that clients are taught in clinics to follow the rules of ARV treatment and Positive Living constitutes a form of 'homework' to which clients must commit. With a medicine companion in the home, a family member also becomes involved in the client's homework. Involving family members and relatives in care tasks is a sense an appropriate method in Uganda, where most sources of care and support are to be found within the extended family (cf. Russel & Seeley 2010). The method is also in line with the high degree of family involvement in care tasks when patients are admitted in a hospital. Finally, for Catholic organisations, it should be noted that visiting ill people at home connects to a long tradition for parish priests to visit sick members of the congregation on pastoral visits.

Many home-based care programmes are also rationalised according to ideas of 'community development'. The employees or volunteers doing home visits are usually referred to with a phrase starting with the term

¹²¹ In other clinics this is called a 'treatment buddy'. The method is inspired by the idea of treatment buddies initially developed by gay communities in North America, as well as the Direct Observed Therapy method used in TB management in developing countries in recent years (Volmink et al. 2000).

‘community’¹²², reflecting the fact they are supposed to be members of the same communities as the clients they are visiting. Community workers are assumed to be closer both in distance and approachability to clients, and to better understand the living conditions of clients. In this way, they are thought to be able to function as links between the clinic and the community, able to identify both problems to be addressed and capacities to be harnessed within the community.

Apart from functioning as links between the clinic and the community, the central role of home visiting is to address the responsibility of the family in providing care and support. Since ‘the home’ is not always a stable, easily identifiable place, and family members are not always supportive homework partners, community workers have to work upon the family members’ sense of responsibility.

Home visiting in Kamwokya Christian Caring Community

For KCCC the discussion of home visiting reflects how home visiting as a practice has been re-cast as ‘ART follow-up’ in the context of the treatment scale-up. Since KCCC represents one of a number of early home-based care initiatives started by the Catholic Church in eastern and southern Africa (see e.g. Blinkhoff et al. 1999), their development may reflect general ways that pastoral care components of home visiting have been reconfigured in the context of growing international response to AIDS.

In this section, I first analyse how home visiting was rationalised and practiced in KCCC according to a number of co-existing and at times conflicting rationales, and then analyse the techniques used during home visits.

Co-existing rationales for home visiting

The practice of visiting people living with HIV/AIDS in their homes was an integral part of how KCCC began, as illustrated in chapter 5. When KCCC was preparing to start providing ARV treatment in 2004, a new ‘home-based care’ (HBC) programme was started, inserting home visiting into to a new context. The rationale of the new HBC programme was officially presented in the following way:

“In June 2004, KCCC started providing antiretroviral drugs (ARVs) to clients living with HIV/AIDS. To ensure effective monitoring and adherence to treatment by clients, adequate care and support by families and communities, the organisation mobilized and trained community based volunteers as HIV/AIDS treatment supporters to assist in this process” (Byansi 2006: 2).

¹²² For example: community health workers, community counsellors, community-based volunteers.

This quote captures the rationality of home visiting in an ARV treatment context as a dual concern: ensuring that clients follow ‘the rules of ARVs’, and producing responsible families and communities assisting clients’ self-government. To most of the community workers in KCCC, this dual concern was also what they defined as their core responsibility.

However, because of connections to previous practices of home visiting and previous programmes in KCCC, discussions around the HBC programme were also informed by a number of other rationales. Symptomatically, the HBC coordinator who has been involved with KCCC since the start, emphasised continuity when he presented the programme to me at my first meeting with the team. He said: ‘The HBC programme was initially started in 1989, they were trained then, but when this programme of ART came, 33 new community health workers were trained to ensure adherence’ (Informal. comm. 12 Dec 2008).

Home visiting and holistic care

Some informants, especially those who have been involved with KCCC since the start, defined home visiting as a practice closely linked to developing and enabling a holistic approach to HIV/AIDS care. As discussed in chapter 5, KCCC informants argued that their holistic approach grew out of an awareness of the many needs of people living with HIV/AIDS as they were ‘journeying’ with them. Building on such a rationale, Christine Namakula, the community work coordinator, argued that home visiting was a method that enabled them to help the clients more holistically, because through home visiting they learned more about the broader social issues the clients are facing:

“we used to visit people at home, and find out how they live, because in a hospital setting, you know, people come in but you don’t know exactly where they are come from. They have to fulfil all the obligations of the hospital, they have to pay the bills, they have to be on the standard of the hospital. But here you know exactly why somebody is as she or he is. He doesn’t have anywhere to sleep, you know . . . water passes through the house . . . when they come in the hospital, you cannot see all this, but when you go to these people’s homes, you find out the best way they live, the best way they interact with each other and be able to help them the more” (Interview 21 Apr 2008).

The point Christine makes here is that if one has to address all the needs of people living with HIV/AIDS and not merely their medical needs, one cannot rely on the ‘logic’ of the hospital alone. One must find other ways of knowing what their needs are. Visiting people in their homes provides a method for acquiring the kinds of knowledge needed to provide holistic care, since in the home setting, one may find (for example) social, environmental, relationship problems – and resources. The counsellor, Elisabeth, made a similar point, when she told me she wished they as

counsellors would conduct more home visits: ‘it would be good because when you reach in people’s homes you understand more about the issues they’re facing and when they come back here, you can have a different kind of counselling, more encompassing’ (Informal. comm. 12 Feb 2009). Elisabeth and Christine’s points reflect the fact that holistic care can potentially become a far-reaching form of government, targeting almost every aspect of a client’s life.

Apart from a method to enable holistic care, some informants also discussed home visiting as a crucial aspect of offering spiritual and emotional support to clients. When the pastoral workers/counsellors decried the neglect of pastoral care in KCCC, they were primarily referring to the fact that they had lost touch with the practice of ‘journeying’: of visiting clients in their homes and being present during their most distressing moments. Anthony said we have “been seeing what we used to do 1990, 1993, is no longer there, people are dying on their bed yearning, nobody is there to offer them a prayer of love”. (Interview 2 Feb 2009). Therefore, reviving the pastoral care component was going to be about identifying weak or bedridden clients and visiting them in hospital or at home to offer pastoral counselling (Interview 2 Feb 2009). Damian pointed out that visiting clients in their homes was left almost entirely to the community health workers, who ‘don’t have capacity for praying and counselling’ (Fieldnotes 2 Feb 2009). As is illustrated below, community workers may not have limited capacities; indeed the issue may relate to their commitment to ART follow-up. More generally, Anthony and Damian located the neglect of pastoral care within the professionalization of KCCC:

Damian: Every day we must thank God to get in touch with Holy Spirit. We have to make them appreciate God to appreciate this treatment. These newcomers don’t know our programme, they are only interested in the salary. Before we were just volunteers. We started getting salaries slowly by slowly from something like 1993-1994. We were all doing home visiting from Francis to Sr. Miriam.

Anthony: After becoming professionals we forgot about home visiting. We need to revitalise it, because when you visit like this it gives them new hope (Fieldnotes 2 Feb 2009).

Furthermore, Damian formulated an opposition between what he saw as KCCC’s ‘roots’ and that of developing ‘programmes’ for the sake of obtaining funding:

In the language of donors it is a programme, but actually it’s a ministry, we are his neck, his hands, his arms. We have to go back to our roots (Fieldnotes 2 Feb 2009).

Thus, in Damian and Anthony’s accounts home visiting is closely connected to the roles of a pastoral ministry embodying the presence of

God through acts of spiritual and material assistance. However, in their experience, due to becoming an NGO, which defines holistic care as specific programmes with objectives, methods, and performance indicators, and which employs new staff motivated by salary alone, operating like a pastoral ministry has been challenged.

However, despite this experience of neglect of pastoral care, there were others among the community health workers and counsellors who perceived home visiting as congruent to the rationale of ‘journeying’. Jagwe claimed that if he had the time and money for fuel for his motorcycle, he would visit some of his clients in their homes, because:

“so many things can contribute to positive living. Just even a mere sharing when you visit . . . then someone is ok . . . just that mere visit . . . can make them comfortable . . . someone cares, yeah the caring itself is really important (Interview 19 Jan 2009).

Similarly, a community health worker, Cecilia, said during the feedback meeting: ‘Our duty is visiting our patients, he may have worry, but when you reach there, they will be happy, saying ‘you’ve saved me, how you talked to me, I have peace, I don’t have any problems’ (Fieldnotes 21 Jan 2009).

The notion of home visiting constituting ‘the roots’ of KCCC was also reflected in the fact that informants in many other programmes and sections of KCCC claimed to be doing home visits. For example the headmaster of the primary school (Interview 1 May 2008), and the coordinator of the Child Welfare department (Interview 22 Apr 2008), claimed that their employees went on home visits. Christine argued that as part of their holistic approach, *all* programmes in KCCC had a home visiting component; social workers, teachers, youth, doctors, nurses, counsellors, Child Welfare officials, and post-test club members all visited their clients at home (Interview 21 Apr 2008). In practice, however, it seemed that in many of these programmes and sections, the employees did not go on home visits so often. The ‘clinic staff’ (the doctors, nurses and counsellors) were for the most part busy with clinical work, leaving little time to go on home visits. Most of the counsellors regretted that, because of the workload in the clinic, they were not able to go on home visits very often, as ‘they were supposed to do’. Elisabeth not only argued that home visiting could enable better counselling, but also that ‘we can’t run away from home visits, it’s what made this organisation unique’ (Informal. comm. 12 Feb 2009).

Community health

The current home-based care programme also has a link to another programme started by KCCC in the 1990s. Some of the community workers for the new programme were recruited from a previous

‘community health’ programme. Up through the 1990s, Christine, who is a nurse by profession, trained over 500 community health workers in different communities in Kamwokya and surrounding areas to mobilise and sensitise their communities on hygiene, sanitation and environmental issues (Informal. comm. 10 Feb 2009). In Kamwokya, these community health workers formed an association called Kamwokya Community Health and Environmental Protection Association (KACHEPA). KACHEPA was involved in things like organising garbage collection (Interview with Doris, 5 Feb 2009), and sensitising women on hygiene and sanitation (Interview with Matilda, 16 Feb 2009).

As a consequence of this link, the volunteers for the new home-based care programme were named ‘community health workers’ (but they were also sometimes called CBVs for community-based volunteers). A rationale that it is also their role to sensitise and involve the entire community on health and environmental issues was prevalent in discussions of the HBC programme. More broadly, there was also the idea that community health workers were general links between the community and the organisation. The HBC coordinator, Mr. Bisase, argued that the community workers were also useful for informing and mobilising the community around other KCCC programmes (Interview 11 Feb 2009).

Emphasis on ART follow-up and linking clinic and home

Apart from the above-mentioned rationales for home visiting, the dominant rationale underpinning the current home-based care programme in KCCC was using HBC as a method to ensure ARV treatment adherence and success. The coordinator of the programme, Mr. Bisase, explained its rationale in the following way,

“it came to our knowledge that these people needed our support from our organisation to enable them to take the drug, to adhere to the drug. When we visit them and find there say for example complaints of the drug, say opportunistic infections, like vomiting and the like, because it could be very difficult for a person in such a situation to come and report directly at the point of service, you know, if we could find any thing going wrong with our people there we could easily come and link, or get the doctor to go with him to our client, and be treated from there for those opportunistic infections. But more importantly it was to ensure that the drug therapy of ARVs are properly taken as prescribed by the doctors, so I think, that’s how the community workers came on this programme of ART” (Interview 11 Feb 2009).

Thus, according to the coordinator, the purpose of home visiting is primarily to ensure ARV treatment adherence, and secondly to provide a link between the clinic and the home to ensure the necessary medical follow-up.

As part of a new work plan for 2009, the HBC team drafted a job description for the community health workers in February¹²³. The job description outlines the responsibilities of the community health workers, and outlines targets for each work task. The job description outlines eleven tasks. Five of these are concerned with ART follow-up and especially with the community health workers functioning as links between the clinic and the home. Two of the work tasks relate to their responsibilities as ‘community workers’, focusing on their responsibility for sensitising the community regarding health issues and their role as community advocates. One task could be seen as connected to the rationale that home visiting is a method for producing knowledge that can enable holistic care: the community health workers are to “document and communicate any social, economic and environmental issues”. Finally, there was also one task relating to their additional duties, which for most of them includes helping out in the clinic with transferring files or working in the clinic reception. The two remaining tasks concern reporting requirements.

These work tasks reflect how the home-based care programme was marked by co-existing rationales and hence divergent expectations. In discussions of the HBC team, the coordinator, the management and the counsellors at times expressed conflicting expectations of the community health workers. Amidst these conflicting expectations, however, their role in ensuring ARV treatment adherence appeared most dominant.

The CHW’s role in ARV treatment monitoring was reflected by the fact that until early 2009, the only people the community health workers visited were those on ARV treatment (‘ART clients’). The new work plan for 2009 included visits to non-ART clients and TB clients among the CHW responsibilities. This change met some resistance and caused confusion among some of the community health workers. One said, ‘some patients are on both ART and TB treatment, but our interest as CHWs is ART, so we may not know if the client is on TB treatment or not’ (Fieldnotes 5 Jan 2009).

In my interviews with community health workers most of them also emphasised their role in securing ARV treatment adherence and functioning as links between the clinic and the home. When I asked what their role and responsibilities were, most of them answered along these lines:

¹²³ The new job descriptions were part of a general initiative in KCCC. After drafting a new 5-year strategic plan in early 2009, the executive director and the human resource manager required all sections to draft job descriptions for the employees with ‘targets’, which matched targets of the new strategic plan.

Cecilia: *“I’ve got to work on clients with HIV, ARVs, see . . . whether they are taking their regiments properly, to check whether they have the right regiments, whether they have enough drugs to see their date of appointment . . . to see that they can come in time for their appointment”* (Interview 30 Jan 2009).

Nansamba: *“they told us that we go visit the patients, count their pills . . . and even asking the caretaker if this patient is adhering to the drugs. . . if you find somebody who’s badly off, you come back and give a report to the doctor, they get a car, they go and carry that patient and bring him here”* (Interview w. translation 11 Feb 2009).

Some of the community health workers also emphasised their role in sensitising the community on health and environmental issues. According to Cecilia, the community health workers’ responsibilities relate to “anything concerning health in the community” (Interview 30 Jan 2009). A few community health workers also mentioned responsibilities, which were not included in the new job description. These were tasks such as encouraging clients to have hope or ‘be firm’ despite their situation, and offering spiritual support.

The community health workers

Before I turn to the techniques of home visiting, I explore how the community health workers were recruited, their employment status in KCCC and their general profile.

According to the community work coordinator, Christine, most community health workers were recruited among those she had previously trained in ‘community-based health care’. According to Mr. Bisase, the new community health workers were recruited among people who were close to “the people whom they are living with, they have a lot of knowledges about their villages” (Interview, KCCC 11 Feb 2009). He explained that they had used two means of recruitment: one was identifying previously trained community health workers from different zones of Kamwokya and surrounding areas, and the other was to go through the Small Christian Communities¹²⁴.

Given that they were recruited on the basis of being ‘active in their communities’, community health workers could be contrasted with other employees such as counsellors, doctors or Monitoring & Evaluation (M & E) employees who were recruited on the basis of a professional identity and education. Community health workers have a position somewhere between a volunteer and an employee in KCCC. They are ‘community-based volunteers’, however they also receive a monthly ‘stipend’ (Byansi 2006:

¹²⁴ Mr. Bisase, who is a Muslim, emphasised though that KCCC was not only looking for Catholics when recruiting the community health workers. KCCC was also looking at other churches and mosques to identify them.

5). Despite their status as community-based volunteers, the community health workers were increasingly required to demonstrate professional integrity and accountability. Management expected them to successfully live up to their role in ‘ensuring life continuation’ (see more below) and fulfil the responsibilities outlined in their new job description. They were expected to meet targets set for their work, to document home visits, to write monthly reports and to faithfully handle money given to cover their transport costs. The increasing demand to plan, report and document posed a challenge to some community health workers who had limited English skills¹²⁵.

The community health workers are assigned a number of clients who they must visit. Their assigned clients usually live in somewhat close proximity to each other. According to the profiling questionnaires I filled with the CHWs, the assigned number of clients ranged from 27 to 58, the average being 39. When I followed community health workers on home visits, we usually visited four to five clients in a day.

Profiles

At the time of my research, there were 27 community health workers working with the HBC programme. Most of them lived in Kamwokya (15) and the remaining lived in nearby areas, such as Kyebando, Bukoto and Mulago. Most of them were women; only four were men, including the coordinator Mr. Bisase. Most of the community health workers were between 40 and 60 years old (the average age was 44 years). Contrary to the ‘professional’ counsellors, most of them possessed limited education. About half of the community health workers had completed O’ level, while the remainder only finished primary school or stopped in the early years of secondary school.

Most of the community health workers were previously involved in the vibrant informal economy in Kamwokya, running small businesses like a bar, a saloon or selling second hand clothes. Most of them still had children going to school, or were putting relatives’ children through school. Over half of the community health workers were Catholic (14), and most of the remaining identified themselves as Anglican or Protestant¹²⁶. Three were Muslims. None of them identified themselves as Born-Again Christians or

¹²⁵ In fact, the community health workers often met the various forms of paper work introduced by management with resistance. In April 2008, I was told that the CHWs had stopped using forms when visiting clients, because it made the clients uncomfortable (Fieldnotes 22 Apr 2008). However, in January 2009, a new home visiting form was introduced that needed to be completed after each visit, however, similarly, after a few days the form was abandoned.

¹²⁶ Protestant often implies being Anglican, unless people specify that they are ‘Born-Again’ or Seventh Day Adventist.

Saved. Eight of the community health workers were also HIV positive. With the exception of Cecilia, these were all ‘clients’ of KCCC.

How ‘community-based’ is home visiting?

In KCCC, the name ‘community health worker’ and the rationales associated with home visiting were, as indicated above, linked to a notion of ‘community’. But whereas home visiting in KCCC initially consisted of small groups of volunteers visiting sick neighbours in Kamwokya, home visits now take place all over Kampala district and beyond. KCCC does not have a residence requirement for clients to start on ARV treatment, unlike the prerequisites of some community-based organisations.

Initially, clients enrolled on ARV treatment lived in Kamwokya and surrounding areas. Today, the official policy is that clients have to reside within Kampala district to start ARV treatment; yet in practice, a number of clients live in neighbouring districts. Additionally, some clients may begin ARV treatment while living in Kampala district, but then later move back ‘to their village’ further away from Kampala¹²⁷. As mentioned above, community health workers live in Kamwokya and surrounding areas, and because KCCC insist on home visiting for all ART clients, the HBC programme and the community health workers face many challenges in managing transport costs. Transport costs were actually quite a contentious topic in KCCC, because in the experience of community health workers, despite some ‘transport facilitation’ they received, they generally had to use some of their own money for transport if they were to live up to their home visiting responsibilities.

Additionally, the task of being ‘community advocates’ and mobilising communities regarding environmental issues seems a difficult one to implement practically when the communities in which they operate are scattered throughout Kampala and neighbouring districts.

Home visiting techniques

Since home visiting in KCCC was primarily defined as a method to ensure ARV treatment adherence and to constitute a link between the clinic and the home, accordingly there was a great emphasis on ‘ART follow-up’ during the visits. However, at times there was an emphasis on encouraging family members to play their part responsibly in ensuring the client followed ‘the rules’. This dual focus is also reflected in the way home visiting is defined as a requirement to start ARV treatment. To begin ARV treatment, clients must accept home visits, and they must also disclose their

¹²⁷ I went with community health workers on home visits in Wakiso and Nakaseke districts. Community health workers and counsellors also talked about clients living in Mukono district and as far away as Luwero, Nakasongola and Masaka districts.

status to at least one member of their household. These requirements are primarily meant to ensure the feasibility of ART follow-up. But the requirement to disclose one's status to at least one household member also reflects the rationale that treatment success will be greater if someone in the home is identified as a 'medicine companion' and charged with the responsibility of assisting the client's self-government. In this section, I first consider the techniques of ART follow-up, followed by the techniques of 'responsibilising' caretakers.

ART follow-up

In KCCC, I followed community health workers on home visits over a period of about two months (three times a week). During home visits, a range of issues could be discussed and addressed depending on the community health worker, the client's situations and their relationship. However, some form of 'ART follow-up' was always included in these visits. In most cases, the community health worker opened the visit (after greetings and general small-talk) with asking to how the client was taking the drugs. The CHW would ask questions, such as 'have you missed any medicine this month?', 'do you take the drugs well?', 'do you swallow once?'. At times, the community health worker would ask the client to take out the pill jars and the adherence card, and the community worker would count the pills to see that the remaining number of pills corresponded to when the client was supposed to come for his or her next appointment. Clients are supposed to mark the adherence card each time they take an ARV pill. It can be seen as a tool to help clients do 'their homework', but community workers can also use it as a method to check adherence. Below is one example of an ART follow-up interaction.

We were on home visit in Bunamwaya with the community health worker Olivia. The first client we visited was a woman in her 40s. She lived in a two-roomed house with two of her children. After exchanging greetings, I introduced myself and the research. Olivia asked the client about her how children were doing, and then she began the ART follow-up:

Olivia: *Can I see your pills?*

While getting the pills, the client was laughing a bit.

Holding one of the pill jars, Olivia asked: *Do you know which one this is?*

Client: *I think it's nevirapine*

Olivia: *If you know it in your head, you can get the drugs if you have gone without them. How are you swallowing?*

Client: *I take two at 8 p.m, and this one I take one tablet at 8 pm.*

Olivia: *Is this the one you started with?*

Client: *No, they just changed for me.*

Olivia: *When are you coming back?*

Client: *on the 18th. I think they even gave me one extra day, because I may fail to get transport.*

Olivia: *Do you have any reactions?*

Client: *I had some in the beginning, but now I'm ok.* (Fieldnotes 10 Feb 2009).

The community health workers' ART follow-up techniques can be understood as a direct extension of the efforts of counsellors and doctors in KCCC to monitor the performance of clients in terms of compliance to the rules of ARVs. The community health workers rationalised the need for adherence checks and pills counting, by claiming that clients could be forgetful or deceiving. For example, Jameela described a typical home visit in the following way:

"I also ask them to have a look at their dosages as most of them keep saying they are taking the doses as prescribed, which might not be the case. So the client and me start to count the medicine tablet by tablet as proof to whether they are taking the dose as prescribed"(Interview by assistant in Luganda, 16 Feb 2009).

This quote reflects that, as in counselling, there were doubts and suspicions about whether clients were behaving as they should. And similar to counselling, much of the authority is in turn vested in the ARV medicine. Counting the pills and checking their proper administration is like a ritual that reaffirms their authority; if you do not follow their rules, these medicines will be harmful instead of 'miraculous'.

Practically, pill counting is no guarantee that clients are actually taking the pills everyday at the same time, as Daniel pointed out (see chapter 6). Nevertheless, pill counting was quite widespread on home visits and appeared to make sense with the 'ART surveillance' responsibility with which the community health workers were charged. Mr. Bisase contended that home visiting helped to produce "a fair monitoring [of] how therapy is done when our clients are given the drugs, because we are able to carry out the pill counting" (Interview 11 Feb 2009). The ART surveillance responsibility of community health workers was reflected in the way their performance, like the counsellors, was evaluated in direct correlation to ART programme indicators, such as levels of adherence, mortality rates and percentages of clients 'lost to follow-up': in sum in their ability to effectively 'save lives with ARV treatment'.

As mentioned in chapter 6, when the executive director presented the new practice of setting targets and standards for the employees' work, he singled out the community health workers' poor performance (here called CBVs for community-based volunteers). He said:

You CBVs have a very big challenge, your patients and your performance has gone down according to the indicators we have put down, a) many of them have disappeared. Why? That means it's either the follow-up or the recruitment. b) so

many ART patients have died, these people are not supposed to die. Those people who gave us the money are saying now, what is the use of these people, when people are dying? How do we justify the existence of these people? One of our roles as CBVs is to ensure life continuation, isn't it so (Mr. Bisase)? (Fieldnotes 27 Jan 2009).

The executive director thus claims that the donor was questioning the continued usefulness and feasibility of the home-based care programme when the ART programme indicators were showing setbacks in terms of 'ensuring life continuation'. That the community health workers' primary role is to ensure ART adherence for the sake of programme success was captured well by Cecilia, who said: "because if they don't take well the drugs, then adherence will be poor, and then . . .we won't be the best, we won't be among the best in the organisations which are working on people" (Interview 30 Jan 2009).

Reflecting the pressure to produce good adherence outcomes among their clients, among the community health workers there was a constant discussion about whether their role was simply to *check* adherence, or whether it was to *enable* adherence. This debate is similar to the tension in counselling between disciplining clients to follow the rules and enabling responsible self-government. When the community health workers were focused on trying to *enable* adherence, it was usually framed as helping with 'psycho-social' problems. The following section looks at how psycho-social problems were addressed.

Producing responsible families

One way community health workers tried to address clients' 'psycho-social' problems such as domestic violence or a lack of income, rent or school fees was to highlight the responsibility of other household members and of a client's extended family (or sometimes neighbours) to try to solve these problems. However, ultimately the responsibilities of family and neighbours were only the focus of a few of the home visits in which I participated.

Probably due to the limited abilities of community health workers to provide practical assistance with problems defined as psycho-social and the challenges of addressing such issues, some community health workers seemed content with merely noting these problems. Their job description stipulated they were to 'document and communicate any social, economic and environmental issues', not necessarily to address such issues. Other times, the community health workers encouraged clients to find strength to overcome such problems by leaning upon and praying to God, as illustrated by the visit in Naguru with Matilda and Beatrice discussed in chapter 7. Finally, considering the sensitivity of these matters, it is possible that

community health workers decided not to invite me on visits to discuss such issues.

The importance placed on responsabilising the family through home visits is reflected by some of the social criteria to start on ARV treatment. One requirement is to disclose one's HIV status to at least one member of the household¹²⁸. Mr. Bisase explained:

“disclosure is a challenge, though it's optional, but there's when he's sick and we're not able . . . that person can easily come to our point of service, so and so x is sick, could you please come, but . . . if they don't know and they have taking the drug badly, how could you know? so, sometimes it does not mean that community health workers to visit daily . . . we encourage these clients to have a caretaker and we expect it from the client” (Interview 11 Feb 2009).

Another requirement is the ‘feasibility study’ of the home setting, which the assigned community health workers must do before a client start on ARV treatment. When Jagwe has finished his ART education with a group of clients, he assigns every client a specific community health worker. Before the client begins the treatment, he or she must go with the assigned CHW to his or her home, to do the ‘feasibility study’ According to Beatrice Asiimwe, the purpose of this visit is to determine with certainty where the client is residing, to know who will be responsible as a caretaker – ‘who will inform us in time in case the client is badly off’, to know the local council chairperson of the area and generally get ‘all the client's details’. The CHWs bring this report back to the counsellors and they note all these details in ‘their book’ (Interview w. translation 28 Jan 2009).

Some of the community health workers emphasised that it was their role to ‘educate’ the caretakers on how to care for and ‘approach’ clients. Jameela for example said “we also have chats with the caretakers to change their attitudes and give ample time and listen to the clients.” When asked what made her pleased in her work as a community health worker, Jameela mentioned among other things, “the case of a caretaker who has changed their attitude and is now handling the client with positive attitude and great care that also gives me joy” (Interview by assistant in Luganda, 16 Feb 2009). In my interview with Cecilia, she narrated a long story of how she had helped a client by approaching her family members with great tact, using various ‘tricks’.

Cecilia had started on ARV treatment at the same time as the client, and therefore Cecilia was wondering why the woman was not improving, *“she had spent a*

¹²⁸ However, there actually were several clients who had not disclosed to anyone in their household. Community health workers explained that they tried to assess the level of disclosure on the first visit, to know how to handle the home visits. Some clients had agreed with the community workers to receive visits in their places of work instead of at home.

year, a whole year without stabilising". Yet, Cecilia knew that the brother the client was staying was a well-off business man, and that he would make sure plenty of different types of food (*apples, oranges, these passion fruits, greens, food carbohydrates, everything*) were sent to the client, before he went to work in the morning.

Cecilia tried to find out why the client was not eating the food or what was going on. By continuing to probe about which foods her sister-in-law prepared for her and how often she was eating, the client finally told Cecilia that her sister-in-law would keep most of the food the brother had bought, for herself and her children. Cecilia first tried to discuss the matter with the client's daughter, but she insisted that the sister-in-law would refuse to let her help her mother.

Consequently, Cecilia later went with a counsellor to talk to the brother. Cecilia said she used a 'trick' with the brother. She told him that since it seemed like the client was not eating, he had to monitor her eating. Apparently the supervision by the brother bettered the situation, and made the sister-in-law change her attitude towards providing food for the client (Interview 30 Jan 2009).

I wish to emphasise two points from this story. First, in KCCC addressing the client's need for proper nutrition is one of the central concerns of responsibilising the home. This is connected to the centrality of proper nutrition for securing antiretroviral treatment success, and that buying special foods for only one person in a household is a point of potential conflict. Second, it seems that when complicated family relations pose a barrier to treatment success, community health workers may involve the counsellors as well. As Cecilia said, when it is beyond 'my capacity' I refer to those 'higher counsellors' (Interview 30 Jan 2009). On another occasion, I went on a home visit with a counsellor and a community health worker to address a similar issue as the one discussed above.

Rose was taking TB treatment and was to begin ARV treatment as well. When Jagwe talked to her at the end of the ART enrolment session, she told him that she had been living with her brother in Kasangati for some time, but now his children and his wife had started to 'mistreat' her, and eventually they had thrown her out of the house. Now, she was forced to stay alone in her own house nearby, which was still under construction. She said *'I am still weak, how will I feed until I am well enough to work for myself?'* Jagwe suggested that he could go and talk to her brother and his wife, only that transport may not be easy to find. Therefore I suggested to take Jagwe and Rose's CHW in my car to visit her and her brother (Fieldnotes 20 Jan 2009).

A few days later, Norah and I went with Rose's CHW Proscovia and the counsellor Esther to visit first her and then her brother. While we were waiting at her brother's compound for him and his wife to return from a funeral, Esther said to me and Norah she would not confront the brother directly with the charges Rose had made about being thrown out of the house by his wife and children. Rather Esther would say she had come to discuss Rose's 'social support system', now that she was going to start ARV treatment (we also agreed that I would not take any notes during their conversation).

Esther encouraged the brother to help Rose with food, because she had just been started ARV treatment. Showing a paper bag with ARV pills, Esther said '*without food, these drugs are like poison*'. The brother seemed concerned that helping Rose with food would require purchasing expensive food; he asked Esther if Rose needed any special foods. When Esther said that the most important thing was to have a variety of foods of any kind they could afford, he agreed to help Rose with food. He said that another brother would bring it to her (Fieldnotes 22 Jan 2009).

The 'trick' that Esther used was thus not to confront the brother and his wife directly with 'their irresponsibility', but to make an appeal to help Rose that was tied to the potency of ARV medicine. Again, the authority of the ARV medicine was used to reinforce the counsellor's plea. Norah met Rose in the clinic about 2 week later, and Rose said that her brother had brought her food once, since we talked to him. Since 'responsibilising' the family can be a complicated affair, there was no guarantee that the counsellors and community workers would be successful. At least, as Cecilia's example illustrated, it might require a continuous engagement.

The fact that psycho-social problems can possibly be addressed by targeting the responsibility of the family reflects that the framing 'psycho-social' not only entails an individualised, introspective technique to handle social problems as I argued in the previous chapter. It can also indicate a more socially embedded form of government, which targets the responsibilities of families to provide the needed care and support.

The home-based care programme coordinated by Ediofe Health Centre

The home-based care programme coordinated by Ediofe Health Centre is organised in a quite a different way from KCCC. In the Ediofe programme, the community workers have no direct relation to the ARV treatment provider. Consequently, they are not held accountable to the same extent as in KCCC to how effectively they 'save lives with ARV treatment'. We might then expect the Ediofe programme to take a different direction and that the community workers emphasise broader issues than 'ART follow-up' in their home visits. However, on a general level there seemed to be more similarities than differences between the rationales and techniques of home visiting in the two programmes.

In this section, I first outline the overall rationales of the home-based care programme coordinated by Ediofe Health Centre. I then provide details about the community counsellors and their position as volunteers. Finally, I analyse techniques used on home visits and compare to those used in KCCC.

Introduction

The HBC programme coordinated by Ediofe Health Centre began in 2004. It was part of a 1-year HIV/AIDS project run by the health centre, with funding from the AIDS Integrated Model District Programme (AIM), amounting to 47 million shillings¹²⁹. Home-based care activities included recruiting and training 25 ‘community counsellors’ and providing them with bicycles. Home-based care kits for the clients were also part of this package. The community counsellors were trained for 1 week. In 2005, the AIM funding came to an end, and the in-charge of the health centre Sr. Paula, an Italian Comboni missionary, applied for funding from the Rotary Club in Trento, Italy to continue the activities. The new project included a refresher training of the community counsellors, five new bicycles, funds for OVC support, but no food supplements as mentioned in chapter 7¹³⁰. To date, the home-based care activities run with no other outside funding, except ‘the token’ of 10,000 shillings Sr. Paula pays the community counsellors at the end of the month, when they bring a report to the health centre (Interview with Jimmy, 29 May 2008).

Ediofe Health Centre does not provide any ARV treatment. The clients assisted by this programme receive their ARV and other medicines, medical follow-up and on-going counselling in the government-run Arua Hospital. The hospital does not monitor the Ediofe community counsellors and there is no direct collaboration between this HBC programme and the hospital.

Home visiting rationales

Prior to the AIM supported project, the health centre provided care for people living with HIV/AIDS only “in a limited form”. Clients would come to the health centre and receive simple treatment for opportunistic infections. According to Jimmy, the idea of developing a home-based programme came from the experiences of trying to help the people living with HIV/AIDS:

“Before that they would come here at the health and we would give them the support we had like treatment of opportunistic infections. . . but what motivated them to come, what forced them to come, there must be a problem at home, that’s why we came up with idea of reaching out to the community through home-based care” (Interview 29 May 2008).

¹²⁹ Apart from the home-based care activities, the project included OVC support, training of HIV counsellors, food supplements to people living with HIV/AIDS and a number of trainings of health centre staff in home-based care, OVC care, psycho-social support and monitoring and evaluation.

¹³⁰ The health centre also began a VCT programme in 2007 with the help of funding from AIDS Information Centre.

Similar to the holistic care rationality of home visiting in KCCC, Jimmy explained that the centre staff wanted to understand more about ‘what forced the clients to come’—in other words, what medical and social problems the clients were having in their home setting. He also emphasised that they wanted to assess and address how the clients were ‘collaborating’ with their families.

As outlined in chapter 5, with the motto ‘the client belongs to the community’ Jimmy emphasised that no single organisation could address all the multifaceted needs of people living with HIV/AIDS and that therefore it was the role of the community counsellors to engage the family and the community ‘to join hands’ to offer the necessary care and support.

With regards to the responsibility of the family, Jimmy argued that since Arua hospital conducted no home visits to provide ART follow-up, it should be the family members who are “educated to supervise the taking of the drugs” (Interview 29 May 2008). More broadly, Jimmy emphasised the relevance of the HBC programme for reducing families’ ‘negligence’ of clients:

“especially negligence of the clients, abandonment of client, suffering in the home . . . maybe even dies without given any support, so this one with the counsellors improved, yeah improved a lot, because if this sick person was there, the counsellor would go to the families, why have you left this one to die? This is still useful . . . when this one was not sick was he not useful to you, so why do you abandon? Let us organise transport and take to hospital . . . so it was through these struggles of the community counsellors that negligence, the level of negligence dropped and this time it is really rare in our catchment” (Interview 29 May 2008).

By arguing that the community counsellors have reduced families’ ‘negligence’ of clients, Jimmy thus highlighted that a key rationale for the programme was to address the responsibilities of families to provide care and support to people with HIV/AIDS. Josephine made a similar point, claiming that their work created ‘harmony at home’. Through the community counsellors’ two main tasks—visiting clients in their homes and ‘sensitising’ their communities on HIV/AIDS—Josephine argued that they helped reduce stigma. Today, people in her community were no longer isolating people living with HIV/AIDS, but ‘staying together’ (Interview 17 May 2009).

With regards to the responsibility of the community, Matthias emphasised the community counsellors’ role in educating the community in order to also reduce stigma and neglect of clients:

“we also educate the community, because at times the community disregard these people who are sick and so on, they look at them like outcast, so it’s our duty is to educate them, say no, you don’t know today it’s his or her, tomorrow it may be

yours, will you be treated the same way? No these people are still human beings, who are still useful in this world, don't think because they are infected, they are no longer human beings, no. . . so we should regard them as human beings and serve them. If they are suffering then we are supposed to help them" (Interview 1 May 2009).

Apart from the similarities to Jimmy and Josephine's points about making the family understand that the client is 'still useful' to them, Matthias' method also demonstrated a more humanitarian fervour. He believed and argued that the community should care for the people living with HIV/AIDS, because they are fellow human beings who are suffering. Matthias is an 'ex-seminarian' and in accordance with his training as a priest he linked this humanitarian impulse to serving God. He said if you fail to help these people, "we are not doing that service which God expected us to do to our fellow human beings" (Interview 1 May 2009).

Main tasks: Home visiting and 'HIV evangelisation'

In line with the overall rationales of the HBC programme, the two main emphases of the community counsellor were to sensitise their community about HIV/AIDS, and visit people living with HIV/AIDS in their homes.

According to the informants, sensitising the community was a matter of addressing stigma and discrimination, but also importantly a way to encourage people to test for HIV. The sensitisations functioned as the primary way for the community counsellors to enrol clients into their care, according to Jimmy. Because Ediofe Health Centre did not provide ARV treatment, they did not have 'their own clients' and the community counsellors had to enrol clients in a different way than being assigned them by the treatment facility. Jimmy explained that because of the sensitisations, people would approach the community counsellors after testing HIV positive or ask the counsellors to accompany them for the testing in Arua hospital (Interview 29 May 2008).

For an ecumenical network of home-based in central Mozambique, Kalofonos termed this practice 'HIV evangelisation'. In this network, volunteers encouraged people to 'convert' to a new truth and a new community of HIV positives, as well as to Christianity at the same time (2008: 171). In the Ediofe programme, there was not an explicit religious conversion element to the HIV evangelisation, but there was a conversion parallel in the way people who were possibly HIV positive were 'converted' to test, and if testing positive, to openly identify as HIV positive. As both Josephine and Jacinto emphasised, people were 'hiding' because of stigma, and as Jacinto said it was their role to encourage them 'to come out, to go and test, those who are positive to come out and accept Positive Living.' (Non-recorded interview w. translation 30 Apr 2009).

Jacinto's statement also speaks to the potential danger of people who have not 'come out' and accepted Positive Living as I discussed in chapter 6. It illustrates how 'knowing the truth' and thereafter 'converting' to Positive Living is promoted as the morally accepted way of living with HIV/AIDS.

Apart from using sensitisations to enrol clients, Matthias also mentioned that he approached visibly sick people and encouraged them to test. Matthias explained: "it's easy to identify, these people who have frequent sicknesses . . . I advise them to come and check their blood and see, it might be the thing" (Interview 1 May 2009).

The community counsellors

With few exceptions, the 25 community counsellors were all people living with HIV/AIDS. They lived in the respective parishes where they were supposed to operate. They came from all six sub-counties of Ayivu county¹³¹, but not all parishes were represented. According to Jacinto Candria, Sr. Paula knew people who were 'living positively' as they came to the health centre seeking medical help and that is how they were recruited. Both Sharon Atiba and Josephine Bugaru mentioned that they were receiving help from Sr. Paula ('she was giving us soap, sugar, rice and salt every month.') and that they were recruited as community counsellors through that connection. Jacinto was one the few counsellors who was not living with HIV/AIDS. He was a catechist in a parish in Pajulu sub-county. Of his own recruitment, he said that he 'was called by Jimmy', telling him 'I've seen you are able to be a counsellor' (Non-recorded interview w. translation 30 Apr 2009).

Matthias Anyako was part of a newly-formed group of people living with HIV/AIDS in his parish, and when the group heard that Sr. Paula and Jimmy were 'organising a training for counsellors', the group identified him to go for the training, as 'someone who could absorb this training and is self-motivated'. Matthias was a well-educated 'ex-seminarian' who had worked for several international agencies (Non-recorded interview 26 Apr 2009). Janet Eduku was also recruited from a group of people living with HIV/AIDS. After her husband died of AIDS, she joined NACWOLA¹³² as a 'discordant member', and then she was 'picked from that group by Sr. Paula to be trained and help community clients' (Non-recorded interview 10 May 2009). These examples reflect how the community counsellors were recruited among patients of the health centre, and by going through post-test clubs and local Catholic Church networks.

¹³¹ The sub-counties are Pajulu, Adumi, Aroi, Manibe, Oluku and Dadamu.

¹³² NACWOLA stands for the National Community for Women Living with HIV/AIDS. The organisation was started in 1992, and soon after its start it opened a branch in Arua.

In contrast to KCCC, the community counsellors had an almost equal gender representation, with 11 men and 12 women working as community counsellors. Because it proved difficult for me to meet a large section of the community counsellors in Ediofe, I did not manage to fill out profiling questionnaires with them like I did in KCCC. However, from the 'reporting chart', which hung in Jimmy's office at the health centre, I accessed some overview information. On the chart the names of each community counsellor was written and their respective parish and sub-county of operation was indicated. Each month Jimmy recorded, on the basis of the counsellor's home visiting reports, how many clients each community counsellor visited that month. The chart showed that some of the community counsellors visited between 3 to 6 clients in a month, while others visited between 7 to 12 clients. Jimmy did not have an overview of how many clients each community counsellors was assigned. The ones I talked to said they had between 20 and 40 clients 'assigned'.

Compared to KCCC, the Ediofe community counsellors go on far fewer home visits. This difference reflects a contrast between how their work is organised and the relationship they have with the health centre. The community counsellors were more clearly defined as volunteers; they lived in their respective parishes of operation and went to visit clients, whenever it suited them and the clients (most of the visits I went on took place on Sundays). As a means of ensuring accountability, at the end of the month, they would provide a report to the health centre and receive 'their token'. The reports were handwritten, often in Lugbara, and included details on the client visited and the 'type of care & support provided' respectively to the client and other family members.

Community counsellors therefore received limited supervision from the health centre. Jimmy mentioned that they were supposed to have meetings between the community counsellors and the health centre to discuss challenges and to know how the counsellors were doing (Interview 29 May 2008). However, during my time in Arua in 2009 no meetings were held and in July 2010, Jimmy contended that they had no funds to hold such meetings, or to do other kinds of follow-up visits in the communities (Fieldnotes 14 July 2010). The problems I experienced with using Jimmy to make appointments for home visits in which I could participate (see chapter 3) may be connected to this rather loose relationship between the health centre and the community counsellors. The fact that many appointments were cancelled at the last moment may reflect that the community counsellors were not as active as they would like to appear.

Home visiting techniques

As a reflection of the overall rationales of Ediofe Health Centre's home-based care programme, the specific techniques discussed by the community counsellors reflected an emphasis on addressing the responsibility of the family and the community. However they did also emphasise their role in monitoring ARV treatment adherence and reminding clients of the rules of Positive Living.

Matthias explained that the clients might forget what they had been 'taught in the hospital' and that it was their role as community counsellors to remind the clients of these teachings (Interview 1 May 2009). Janet mentioned how she concluded her home visits by checking the client's 'treatment book' and the pills, in order to confirm whether the client was keeping appointments and taking the pills correctly (non-recorded interview 10 May 2009).

An example from one of the few home visits I attended helps establish a general picture of such techniques. On the visit, Jimmy and I were following Proscovia Enyaga on home visits¹³³.

We were visiting an elderly women living by the trading centre in Ediofe. When we entered the house, we first met with one of the client's daughters. She was introduced to me as the client's 'caretaker'. Greetings were exchanged and there was general small talk about how the client was doing medically. When the client entered, she added details on how she was doing; she said she had 'weak legs' and sores in her mouth. The client then took out her pills jars and adherence card and Jimmy checked them. Then followed a long discussion about how the caretaker and the client were cooperating. At the end of the visit, Proscovia concluded with a little speech about how the client should 'comply with the treatment', saying things like *'take it every day, and because these drugs are strong, make sure to eat something everyday'* (Fieldnotes 18 Mar 2009).

Thus, in similar ways to the 'ART follow-up' methods used in KCCC, Jimmy checked adherence by scrutinizing the pills jars and the adherence card, and then Proscovia concluded with a reminder of 'the rules'. There was additionally a focus on how the client and the caretakers were 'cooperating', which I discuss below.

On other visits I attended, Jimmy usually asked the client how the particular community counsellor was helping him or her. Their replies indicated that reminders about 'the rules' were central during the home visits. For example, a female client we visited with Jacinto said: 'The help of the counsellor is that he gives me counselling that is how to live

¹³³ Proscovia was also the chairman of the post-test club that meets at Ediofe Health Centre. I did not get a chance to interview her, because she fell ill with TB shortly after this visit. In July 2010, I learnt that she had died from the TB.

positively and to comply with the drugs I'm taking, don't miss and whenever I'm sick I shouldn't stay long at home' (Fieldnotes 4 Apr 2009).

The way the Ediofe community counsellors were reminding the clients to do their 'home work', is similar to how the community health workers in KCCC were extending the disciplining of clients from the clinic to the home. However, in contrast to the community health workers in KCCC, the Ediofe community counsellors conduct this ARV treatment monitoring as more or less self-proclaimed authorities, since Arua hospital have not charged them with this responsibility.

The Ediofe community counsellors also emphasised their role in addressing the responsibility of the family to provide the appropriate care and support for their clients. One example of this emphasis, was the way Proscovia, on the home visit mentioned above, encouraged the daughter to have patience with her mother. She said to the daughter: 'Don't be annoyed, the character of clients can change, they can become annoyed if you delay with food, when they are hungry' (Fieldnotes 18 March 2009).

Janet explained how she would encourage the family to take good care of the client by showing by example. Janet said that sometimes she visited clients who had not eaten for two or three days or who were bedridden, and then 'we eat together and show them that love, when they are sick, we also fetch water, we can wash them; the family members fear to wash their clothes, 'oh,oh it has the virus''. She explained that she did things like eating with the client or washing his or her clothes to demonstrate to the family members that it was safe to do so. She concluded: 'we want the family members to love them like we do' (Non-recorded interview 10 May 2009).

In the interviews, the community counsellors did not talk much about how they could address the responsibility of the community, apart from the fact that they believed that the sensitisations reduced stigma. However, on a home visit with Mathias in Aroi sub-county, the central issues were both efforts at securing appropriate family support, and the role of the community in doing so.

As we walked towards the client's house, Mathias told Jimmy and me that the client was a widow. Her deceased husband had two wives both from DR Congo. When the man died the widows were struggling. In November last year one of them died. *'Now this one is left alone to suffer. The father-in-law tries to help, but he also has his own responsibilities'*. Mathias explained that woman is now 'an orphan', nobody had inherited her, because *'here when widows are known to have this disease nobody will inherit them'*.

We met the client and the father-in-law, and Mathias introduced Jimmy and I. Immediately, Jimmy began a long speech, thanking the father-in-law for taking good care of the client, and not just chasing her away.

During the visit, Mathias told us that he encouraged the client to ‘keep going’: *‘that she can continue to live here in the father of her children’s village, because I know if she goes to DRC, she will not be able to access treatment’*.

To this Jimmy said: *‘Now, the client belongs to the community, is there any LC¹³⁴, an elder, any organised help towards the sick? Mathias replied: No, there is no such thing here. People here see them as outcasts. Poverty levels are so high here. People say I’m being defeated by poverty, how do I start helping that one?’*

Later in the visit Jimmy returned to the question of community responsibility. He asked Mathias if the parish church organised any help for the sick and needy. Mathias replied that there is nothing much like that here. And Jimmy then encouraged Mathias to take up the issue of support for the sick at a local council meeting in the future. Mathias agreed, and said:

‘After some time, this ideology will come, that it is not for people outside to help people like her, that the community must come together and help such people’ (Fieldnotes 26 Apr 2009).

The interaction between Jimmy and Mathias demonstrates how Jimmy was also trying to render the community counsellors responsible for ‘responsibilising’ the community in their respective parishes of operation. As a comment to the discussions in chapter 7, the ‘ideology’ which both Jimmy and Mathias promote here is one of not ‘begging’ outsiders for help, like begging for food support and special services for people living with HIV/AIDS, but one of the community coming together and taking care of ‘their own people’. It is thus a development rationality, where the community takes on the responsibility for helping themselves instead of relying on outside support.

The Ambassadors of Positive Living at work

In this section, I turn to a discussion of the common use of HIV positive volunteers in home-based care programmes, in order to approach the practice of home visiting from another angle. In the HBC programme coordinated by Ediofe Health Centre almost all the community counsellors were people living with HIV/AIDS, and in KCCC some of the community health workers were. Using HIV positive volunteers to do home visits raises questions about the role they are expected to play as community workers, and about the possible challenges and implications of involving HIV positive volunteers in treatment and care programmes.

In this part of the chapter I argue that the HIV positive volunteers doing home visits can act as Ambassadors of Positive Living, functioning as

¹³⁴ LC stands for Local Council (Chairman). A local council is a form of elected government within districts in Uganda. They were initially established as ‘Resistance Councils’ by the NRM government. There are five levels of local councils; from the village level 1 to the district level 5.

living examples of how following the rules is possible and beneficial. This section functions as a beginning to the examinations of identities and socialities, which are central to the ways people living with HIV/AIDS try to realise the potentials of ARV treatment and Positive Living. By considering the positions negotiated by HIV positive volunteers, I point to both the potentials of becoming an Ambassador for crafting a new identity, and the importance of social differences in the ability of people with HIV/AIDS to follow the rules.

A living example

The idea of recruiting people living with HIV/AIDS to play an active part in AIDS programmes has been on the international agenda since the mid-1990s (Nguyen 2005). Initially, the method was thought to make AIDS intervention more effective, to reduce stigma and to ‘empower’ people living with HIV/AIDS (e.g. UNAIDS 1999). In providing home-based care, the rationale of recruiting HIV positive volunteers is more specifically that, because they have similar experiences to clients, they are able to establish a close relationship with clients, and they are able to function as practical examples of how ‘following the rules’ helps to prolong life.

Explaining how the Ediofe community counsellors ‘enrol’ clients by encouraging people to test for HIV, Jimmy said: “most of the 25 community counsellors are positive people, such that things can be done, smoothly, yes if somebody was not positive and goes to learn about your status, I think you will not be happy to tell him” (Interview 29 May 2008). In KCCC, the counsellor Daniel argued that people living with HIV/AIDS are ‘good community mobilisers’. Mentioning how they give their testimonies during sensitisations, Daniel added; “in fact they are good examples of living testimonies what they have gone through, actually others can learn from them” (Focus group discussion 12 June 2008). Other participants in this focus group discussion made similar points. For example, an M & E official said: “people are living after 20 years, and people live productive lives. So these people encourage others to come, to come out and get the treatment and live positively, as long as God permits” (Focus group discussion 12 June 2008).

In this section I first discuss the way some of the community workers from both programmes were rather exemplary Ambassadors of Positive Living and how they could use this to encourage clients to follow ‘the rules’. Secondly, I consider the challenges some of them faced in acting as living examples.

Beatrice Asiimwe

KCCC's Beatrice Asiimwe was one of those who embodied the role of Ambassador of Positive Living particularly well. At the time of my research, Beatrice was 43 years old. She is a client of KCCC who lives in Kamwokya. She tested HIV positive in 1994 after her husband began to fall sick. She started as a community health worker in 2004 when KCCC began providing ARV treatment. She had been on ARV treatment for 2 years.

Beatrice emphasised that she used her own status to establish a close relationship with her clients: "the relationship I build is that I first tell them that I'm also like them, some of them I show my reports, sometimes I show them my drugs". She also explained how she used her own life story and her own success in taking ARV treatment to demonstrate the positive outcomes of following the rules: "I advise them to take their drugs well, because they see the way I look, I give them my testimony . . . I tell them 'look at me, my husband died and left my children when they were in primary 3, now they've finished the university'" (Interview w. translation 28 Jan 2009).

'The testimony' is a central aspect of how people living with HIV/AIDS function as Ambassadors of Positive Living both in sensitizations and on home visits. In KCCC and the Ediofe programme it seemed clear that those who mastered the art of 'testifying', also worked well as Ambassadors. Beatrice often gave her own testimony during home visits and also in my informal conversations with her. During the visit discussed in chapter 7, she used her own life story to encourage a client to persevere and hold on to God. On other visits, she used her life story to encourage clients to disclose their HIV status by illustrating all the positive outcomes she had experienced from disclosing. Like she told me 'disclosure is good, if you don't disclose how can people help you. If I talk to M&E, I disclose, now they're even paying half my school fees' (Informal comm. 9 Jan 2009).

As also observed by Nguyen, there are parallels between 'the testimony' of living with HIV/AIDS and evangelical forms of Christianity (2009b: 372), both of which spread on the continent at the same time. Testimonies often follow a similar narrative structure as conversion narratives. 'The testimony' often starts with the individual being in a state of crisis (recurrent illnesses and/or suspicion of HIV infection), and therefore seeking restored significance and health. Through meeting a new community (e.g. a treatment programme or a post-test club) and learning new techniques to deal with the crisis (Positive Living rules), the crisis is integrated into a new worldview (Jørgensen 2006: 2; cf. Grunwald 2006). In my interview with her, Beatrice told her life story like a testimony.

When my husband knew that he was sick . . . I started sensing it . . . I saw he was having fever all the time . . . he was taking drugs all the time, getting tests . . . then I have a headache . . . what I did . . . I went to the church elder, and I told him, they advised me to go for blood test, I did it immediately and I knew, I started getting education. At first I was discouraged, I was badly off, I lost weight, I hated myself, I wanted even to commit suicide, but because counsellors had started coming up, I got those who encouraged me and I started from there, by the time he got bedridden, I treated him, when I was already bold, until he died, I continued with my treatment, whatever pain I would get I would run to the doctor immediately, if I get any confusion I would run to the counsellors, that is what has helped me to stay up to today. . . I started disclosing in 1998, that is when I fully disclosed . . .

Louise: Why did you decide to disclose at that time or what gave you the courage to disclose?

Beatrice: It is the teachings (mesomo) we were being called, in those workshops, I would attend every workshop, I didn't miss any, then I joined this post-test club, that is when I got the confidence and boldness like my friends I found in those post-test clubs (Interview w. translation 28 Jan 2009).

By giving such a testimony to clients, Beatrice exemplifies that one can overcome feelings of self-hatred and discouragement, and if one does so and always runs to the counsellors for advice, one can live long with HIV. Her testimony also illustrates the potentials of openly and publicly declaring HIV positive status; there are opportunities to access support (in her case school fees) and the potential to become a kind of 'Positive Living star' (cf. Meinert et al. 2009: 202). Through Beatrice's example of successfully embodying Positive Living, her clients may find inspiration and courage to openly disclose their status. For Beatrice, forms of bio-sociality seems important, as she stresses the confidence she learnt from other members of the post-test club.

Josephine Bugaru

Josephine Bugaru, from the Ediofe programme, was the first person in her little village in Adumi sub-county to publicly announce that she was HIV positive. She tested in 2000 after she returned from a job in Kampala, with her husband who had started to fall ill. When her husband died a few months later, her in-laws chased her off the husband's land. She was now back at her father's land. She never had any children of her own, but since she moved back she has been taking care of her deceased brother's 12 children. She had been on ARV treatment in Arua hospital for the last 2 years.

Her position in the village as not only the first one to openly live with HIV, but also one who did so with stubbornness and defiance seemed to have given her a special status. She explained that at a time when other people living with HIV/AIDS, "refused to come out openly, and they refused to go

for testing, even to access drug”, she felt compelled to ‘shout her HIV’ even in the face of ridicule and stigmatization:

people were just laughing, when we used to go for treatment, people ‘eh, come and see how HIV positive people look like’ . . . I said that ‘yes, I’m here, you come and see, so that you don’t get the virus, I should be the first and last this is how HIV can affect us, whether I’m HIV positive I can still eat, I’m still useful . . . right now I’m weak, God wiling I will be stronger, I will do things more than this one, people thought I’m dreaming, but their dreams became true, right now, they’re saying . . . God’s miracle, say that ‘no it was not God’s miracle, if you really have trust in you, God will help you in that trust, if you don’t have trust in yourself, you will even die . . .

She further explained how through her own defiance of death and stubborn insistence to keep going assuming she was going to live and not die, she managed to stay alive:

when I was really sick, when I was discharged from Adumi health centre, I came home, I started digging . . . people were saying, you are stupid, do you think this cassava you are digging will get you alive? I say that if I die people will eat in my burial, ‘ah, do you think your burial will get this cassava?’ I say that no even if my burial will not get this cassava, the one they use in my burial will be replaced by this one (laughing) . . . , sure enough, when I started harvesting the cassava, people say ‘eh, you really have hope, we thought you were not going to see this cassava, now you’re also eating this cassava, eh!’” (Interview 17 May 2009).

Stubborn, outspoken and successfully following the Positive Living dictum of staying alive through sheer determination, Josephine embodies the possibilities of living positively in her village. She claimed that she had become an example for others in her village to follow, saying things like she was ‘a medicine’, ‘the key’, ‘a light’ for others. For example, she said:

“And people are now coming to me, those who are hiding, so I’m just to them like a medicine, they were just saying that ‘now this girl, in those days, we thought that she was not going to come up to this extent, now look at the strong heart she has, she’s able to come up to this time and she is also now helping these children whether she’s sick, but still living and she’s still useful to this community, to the family and so on’, so very many of them have started to come up now” (Interview 17 May 2009).

Having lived for long with HIV, still ‘being useful’ by taking care of her brother’s children and helping her community as a community counsellor, Josephine practically embodies the possibilities of living positively with HIV. Josephine’s insistence on ‘shouting her HIV’ seemed to have been a successful way for her to craft a new identity. Mirroring the religious parallels of testimonies, she talked about HIV as ‘her gospel’:

“Some people keep quiet, why do you shout yours? I say, ‘yes I must talk to my HIV (laughing) . . . ‘ah, yours is too much, all the time you go there HIV, if you see very many people, HIV, if you’re going on the way, HIV’ What’s wrong with?

I say that, that one is my spread, I can just spread that gospel” (Interview 17 May 2009).

The examples of Beatrice and Josephine reflect how publicly declaring one’s HIV status and ‘spreading the gospel’ of Positive Living may constitute an opportunity for people living with HIV/AIDS to regain a morally accepted status within their local communities.

Ediofe: ‘attracting’ clients by being a successful Ambassador of Positive Living

For the Ediofe community counsellors being a successful Ambassador of Positive Living seemed central to their success in enrolling clients into their care. Among the few Ediofe counsellors I interviewed, there were visible differences in their ability to function as living examples. Josephine and Matthias appeared to act most successfully as Ambassadors and accordingly they had more clients ‘assigned’ than the others I interviewed. Matthias said he had over 30 clients from across Aroi sub-county and Josephine said she sees over 42 clients. Matthias explained how he attracted clients from though word-of-mouth:

“there are some of these clients who go and tell their friends that so and so helped me out of my problem. I had a similar problem, but when I went to so and so, he helped me, identified me a channel, and I went through, I’m now successful, so if you are having a similar problem could you perhaps see him, then some of them come to see me, through that way” (Interview 29 May 2008).

In contrast, Jacinto and especially Sharon seemed less successful in attracting clients. Jacinto had 18 clients. He was a catechist, who, despite emphasising the need for people possibly living with HIV/AIDS to ‘come out of their hiding’, personally refused to test for HIV. About his recruitment of clients, he said ‘After VCT some of the clients go via me to reveal their results, most especially those who test positive’ But, he also contended that there are some who ‘test positive and don’t come to me, I just leave them there, I don’t force them’ (Non-recorded interview w. translation 30 Apr 2009). Sharon appeared to be struggling to personally follow ‘the rules’ of Positive Living. She told me she had problems with her husband, who had found a new wife, and also that she stopped taking her ARVs; ‘because my husband follows me whenever I take this drug, threatening to beat me, saying I’m intimidating him ‘that you give me HIV’, so he has several times stopped me from taking the drugs’ (Non-recorded interview w. translation 30 Apr 2009). Sharon only had 4-5 clients and according to Jimmy she was ‘not very active’. In July 2010, I learned that someone else had replaced Sharon, because she had moved away from the area.

Challenges to being a practical example

Sharon's experiences illustrate how following 'the rules' of Positive Living can be difficult also for the Ambassadors. Both the KCCC and the Ediofe community workers mentioned instances of struggling to live up the ideals of Positive Living. Several of the community workers (and counsellors) in KCCC had experienced challenges with disclosing their HIV status, and some had only partially disclosed.

In KCCC, Cecilia was in some respects a successful example of Positive Living. Cecilia received her treatment from JCRC, which she started to do in 2003 as part of a research project. She was among the more educated community workers, having completed O' levels, and before she fell ill in 2000, she worked as a security guard at the American Embassy. She said that her own transformation from being 'totally down' to recovering with the help of ARVs, had encouraged others, who otherwise feared initiating ARV treatment. But she wondered why they, as community health workers, were paid less than, for example, the counsellors. She pointed to the limited stipend as a barrier to her caring for herself and all those who depended on her:

"At times there is when you move and you don't have nothing to drink, you are thirsty, what, but nothing you can do, you are there to survive . . . although they give us some stipend here, they take it as to be transport, but we find it also it's not enough for us, you have children going to school, we all have people to support at home, for example me now I have someone at the university, 2nd year, I have someone in S6, I have an orphan on ARVs, I have myself on ARVs [chuckling], so there is another person coming staying with me, so I find it a problem also, it's not easy, so those ones, that one is my own problem" (Interview 30 Jan 2009).

Similarly, Matthias talked in length about how poverty made it difficult for counsellors to act as living examples. After talking about how paying school fees for his five children was 'going to defeat him', and how he wished they as counsellors could get access to a job or some capital, he said:

"So these are problems we counsellors face: poverty. We should be living exemplary, because we are helping these people. Because of the very people you are helping see you not getting out of the problems you have, then it is a mockery it doesn't, it doesn't prove that what you are teaching them is. . . at times it is your practical example that is going to impress, to put weight. . . So some of us also ourselves are poor, we live in those conditions, so we don't know how . . . we could put flesh on the skeleton, that is what is happening" (Interview 1 May 2009).

As Matthias points out here, many of the community counsellors, like their clients, struggle to overcome so-called 'psycho-social' problems. When they try to encourage their clients that such problems *can* be overcome with

changed self-perceptions, prayers or referrals to the right channels of support, it is a huge setback that they themselves cannot overcome such problems. Consequently, they may fail to prove that living positively works.

Negotiating positions

Despite the challenges HIV-positive community workers sometimes faced in practically embodying Positive Living, it is remarkable how being a community worker in both KCCC and Ediofe earned them a position of authority and even popularity in their local communities. Like the community-based distributors of family planning in Western Kenya, discussed by Kaler & Watkins, being a community worker provided a way to engage in ‘the production of respect’ – “they could become well-known and respected for working to make a village a better place and helping families to live better lives” (2001: 259).

In KCCC, various informants mentioned how the clients sometimes referred to the community health workers as their *musawo*, or their ‘counsellor’. The Luganda word *musawo* means doctor, but it is used in broad reference to any health worker. When the clients called their CHW ‘their *musawo*’ they were corrected, because the community health workers are not ‘real’ health workers or ‘real’ counsellors, but often “they insist that you are my *musawo* and without you I would not have life because it is you that have been there for me” (Interview with Jameela 16 Feb 2009). The phenomenon of referring to a CHW with a term for a medical authority reflects how they gain a position as authorities on Positive Living.

In addition, some KCCC community health workers who are not HIV positive appeared to have gained status and popularity. During a brief visit in July 2010, I learned that a number of KCCC employees were going to run for local council offices in Kamwokya¹³⁵. One of these was the community health worker Jameela. When I asked her about it, she said ‘you know when we do this community work, we become so popular’ (Fieldnotes 7 July 2010). This point reflects how volunteering as a community worker holds potential as a stepping stone to better jobs (cf. Swidler & Watkins 2009).

Matthias Anyako

Becoming a community counsellor seemed to have given Matthias not only an opportunity to integrate his HIV positive status into a new moral order, but also to overcome earlier disappointments in life. Matthias is a widower

¹³⁵ The others who were going to run were the Executive Director and the Coordinator of the Primary Health Care department (previously the M & E coordinator). They were all running for these positions on a Democratic Party ticket.

who is around 60 years old (his wife who was also HIV positive recently died of cancer). In his youth, he studied to be a priest in the Catholic Lacor seminary in Gulu. But he never became a priest, because his father fell ill, and ‘he had to come back and support the family’. Since, he has worked for international agencies like UNDP, FAO and UNCHR with logistics and administration. He had been on ARV treatment since he tested positive in 2004.

Matthias pointed out how being a community counsellor had made him many more friends and made him popular in his local community, and that it was especially the practice of ‘testifying’ during sensitisations, which had helped him become popular and known around the sub-county and beyond. But he also pointed out that being a community counsellor has given him a second chance of fulfilling his calling to serve people’s souls:

“As an ex-seminarian I was supposed to serve people’s souls, but because I was not able to become a priest, well I’m now saving their lives, by advising them to go for treatment and so on, so I’m already doing one of the vocations, that one makes me very proud. I’m still useful even though I didn’t become a priest”
(Interview 1 May 2009).

Thus as a community counsellor, Matthias had found a new way of being useful and important in his community, which not only built upon his HIV positive identity but also his identity as an ex-seminarian. When Matthias becomes a successful Ambassador of Positive Living he can function as a practical example of how people living with HIV/AIDS can not only ‘still be useful’, but perhaps also useful in new ways.

Negotiating responsibilities in the home/the community

As local authorities on Positive Living, the Ediofe community counsellors, however, also have to deal with great expectations from members of their respective communities. Because of the way HIV/AIDS interventions and HIV counsellors are associated with access to resources in Uganda, many community members expect that community counsellors are in a position to assist in various ways. Jacinto explained: ‘people think we are working for money, they come and ask for help from us, they want us to help them with money. But we are doing this work voluntary, but people don’t accept, they say you come to give monthly reports, you should be given some money’ (Non-recorded interview w. translation 30 Apr 2010). This point illustrates the flip side of becoming popular in their local communities; now community counsellors may also be considered ‘big people’ one can approach for support.

It was especially in relation to organising transport to Arua hospital in cases where clients needed to be admitted that community counsellors felt challenged by the expectation of clients’ family members or relatives.

Josephine explained that the relatives think they are ‘everything to the clients’

“ . . . now if that person is sick, you are the very person to take him to treatment, so that one is a big challenge, they thought that we have cars, we could just go and pick this thing, from home, at hospital you go and cater for that client and bring him back like that” (Interview 17 May 2009).

The problem Josephine identifies is here is that the relatives do not seem to understand that they are simply volunteers, who can offer only counselling, consolation and advice regarding other avenues for support. The way the community counsellors problematised family member’s expectations also reflects how they see their role as a matter of ‘responsibilising’ the family. Janet said:

‘Like there was a client who died, she was seriously bedridden at home, they expected I would get transport ‘you are a counsellor, how can you tell us to get transport? They expected me to get a vehicle. I went to AHAP and came with the vehicle, when she was admitted they thought I should look after her. They don’t understand this work’ (Non-recorded interview 10 May 2009).

So despite the rationale that home-based care is meant to responsabilise the family and community to pull together resources to provide care and support to the clients, the community counsellors sometimes fail in this regard, producing instead the expectation that they as local authorities on Positive Living are responsible for clients and have (perhaps unlike the family or community) access to resources to fulfill this responsibility. In other words, the community counsellor may fail to produce responsible, self-reliant families and instead produce expectations of them as patrons.

‘What medicine are you taking?’ – indicators of social difference

It is important to note that not everyone has the opportunities, skills or social connections to become an Ambassador. In KCCC, because community health workers do receive a small stipend and may have the opportunity to access various forms of social support from the organisation¹³⁶, it is possible that they are in a better social position than the clients they visit. Consequently, the HIV positive CHWs may find it easier to live according ‘the rules’ than some of their clients.

The fact that successful Ambassadors of Positive Living may illustrate levels of social difference between them and ‘ordinary’ clients was reflected by the suspicion among clients that the community health workers were ‘eating’ money that was intended for them. During the feedback meeting, Beatrice explained: ‘When we go to our people, we get a problem,

¹³⁶ Beatrice for example mentioned how she accessed help with school fees for her children by approaching the M&E coordinator.

when they're in that situation of hunger, they expect you have come with something, they get annoyed "you don't bring us the money, you eat them" (Fieldnotes 21 Jan 2009). Such reactions from the clients reflect perhaps the widespread experience in KCCC, mentioned in chapter 7, of a feeling of entitlement to support, which failed to materialise. However, the way Anastasia explained such reactions from clients, it seems clients are rather pointing to the social differences between themselves and HIV-positive community workers. During the meeting, she explained how hunger made some clients get very harsh with her and say things like:

'leave me alone, they give you our money and you eat. . . . For you, what kind of drugs are you taking? You look better than others'. You explain that if you follow the rules well..... they still insist, we're eating their money 'what have you brought for me?' (Fieldnotes 21 Jan 2009).

According to Anastasia, because of the differences between community workers and particular clients in their ability to follow the rules of Positive Living, some clients wonder whether the community health workers receive better medicine than them. In the interview, Anastasia elaborated this point:

"I first introduce to them, I disclose who I am, some of them do not agree that we are sick, some of them say that we are, we are just lying eh? We want to come and take this medicine, then even others say that we are taking another type of medicineBecause for us we look very healthy, we are fat, it seems we take a different drug, which is different from what they take, an example is a lady I swallow with, me I move with my drugs, I asked her what do you swallow? She told me nevirapine or efavirenz and truvada, and I opened my bag and showed her , you see what you're talking about, this is what I walk with in my bag, do you see any difference? But they don't believe that we swallow the same drug, they think because we are workers here they give us some special medicine, which is different from theirs" (Interview w. translation 11 Feb 2009).

Thus while HIV positive community health workers may successfully embody the miraculous effects of ARV medicine, they may also symbolize social difference – that due to differential access to resources and the right social connections, some are able to benefit the life-prolonging potentials of ARV medicine, while others struggle to do so.

Chapter conclusion

This chapter has illustrated how the home-based care programme in KCCC and that coordinated by Ediofe Health Centre constitutes both a form of monitoring of clients to follow the rules of ARVs, and a form of 'responsibilization' of the family and the community to assist clients' self-government. Home visiting is in this sense a practice, which is considered crucial in both KCCC and Ediofe Health Centre, to make it possible for

ARV treatment to be successful in resource-limited settings. Because of organisational differences between the two HBC programmes, community workers in KCCC emphasise ART follow-up more than family responsibility, while the Ediofe counsellors emphasise family and community responsibility more than ART follow-up. The Ediofe community counsellors have no direct relation to the ARV treatment provider and a looser relation to Ediofe Health Centre than the community health workers have to KCCC. Consequently, the Ediofe counsellors are not held accountable to the same extent as in KCCC to how effectively they 'save lives with ARV treatment'. In contrast, as community counsellors with limited supervision and support, they must handle challenges and community expectations more independently.

Being a community worker in both KCCC and Ediofe provides an opportunity to become respected and popular within their communities, to learn new skills such as counselling and 'testifying', and for those who are HIV-positive, a possibility to regain a morally accepted status in their local communities as an expert on Positive Living. HIV-positive community workers can find new ways of being 'useful' by functioning as practical examples of Positive Living to their clients or in their communities. However, the limited remuneration the community workers receive for their services is not always sufficient for them to live exemplary lives, and some HIV positive community workers struggle to successfully function as Ambassadors of Positive Living. But, with status, respect, the little salary, and the social connections that come with volunteering, community workers may also maintain a social position superior to that of most of their clients, producing new expectations of them as patrons or producing jealousy.

9. Being and becoming a client

Introduction

The previous chapters have illustrated how the dominant forms of government in the three Catholic organisations centres around disciplining and educating clients to follow the rules of ARV treatment and Positive Living. Furthermore, I have illustrated how counsellors and community workers try to foster self-reliant clients, families and ‘communities’ who responsibly address any social or economic barriers to following these rules.

As discussed in the previous chapter, some clients can access opportunities for employment and positions as local authorities by becoming ‘Ambassadors of Positive Living’. However, the majority of the clients I encountered were struggling to work out ‘the rules’ in the context of the home and within family and kinship relations. Therefore, I follow Meinert et al. (2009) in their argument that it is rather the socialities of kinship and clientship than forms of bio-sociality, which appear central to most clients. The overall argument pursued in this chapter is that people living with HIV/AIDS must balance their attempts to realise the life-prolonging potentials of Positive Living and ARV treatment with ‘following the rules’, i.e. demonstrating that they follow the self-government required of them as clients.

Based on the ethnographic approach to social technologies discussed in chapter 2, this chapter first analyses the uneven ways that people possibly living with HIV/AIDS accept to ‘become a client’ in treatment & care programmes. The second part of the chapter is an analysis of how clients attempt to realise the life-prolonging potentials of Positive Living and taking ARV medicine in their own lives, focusing especially on those clients who in various ways struggle to benefit from these potentials, and those who critique, negotiate, or find other paths holding greater potentials than following ‘the rules’.

These discussions provide an indicative analysis of the ways in which ‘treatment, care and support’ practices such as those pursued by the three Catholic organisations contribute to the production of new uncertainties of living with HIV/AIDS, and new inequalities between those who can successfully follow the rules and those who cannot. Because my fieldwork focused on participant observations of counselling and home visiting, the extent to which I gained an understanding of how people living with

HIV/AIDS engage with the programmes as ‘clients’ in the broader context of their everyday lives is somewhat limited. Rather than an exhaustive, in-depth analysis, this chapter provides a broad analysis suggesting a number of problematics.

Becoming a client

With the increasing access to ARV treatment in Uganda, becoming ‘a client’ in a treatment programme in order to access treatment and Positive Living advice has become a dominant way of responding to the prospects of living with HIV/AIDS. However, even with its dominance there are still many people who consider the prospects of becoming a client with reluctance and fear (see also Mogensen 2010). When this section analyses the uneven ways people choose or accept to become a client, it speaks of the ‘uneven seepage’ of medical technologies (cf. Rapp 1999), and highlight the point that despite the dominant forms of government, I have identified, they do not produce the same effects for everyone (cf. Jönhcke et al. 2004).

The first step in becoming ‘a client’ is to test positive for HIV. Therefore, I begin this section with a brief analysis of the testing process. Thereafter, I analyse how becoming a client is not merely a question of responding to misfortunes or suspicions but tied into questions of identity and social position: different groups of people find that taking on an HIV positive identity is a potential for new life chances, while others find it a hazardous affair.

‘Be tested and then you can start planning your life’

In Uganda, as in many other African countries, testing for HIV has largely been promoted as a service you voluntarily seek out. HIV testing has for long been offered in ‘Voluntary Counselling and Testing’ (VCT) programmes. One exception is the routine testing of pregnant women in connection with antenatal care, which is used to estimate prevalence rates. In recent years, there has been a greater emphasis on such ‘Provider-Initiated’ HIV testing (Kyaddondo 2009; Yeatman 2007; Weiser et. al. 2006) in response to the need of identifying and enrolling ‘the population’ to be saved with ARV treatment (Nguyen 2009b: 208).

However, still, the emphasis in counselling and in HIV/AIDS sensitisations is the promotion of testing for HIV as an ethical project. You must know the truth of your own and your partners’ sero-status in order to live ‘safely’ – either *staying negative* or *living positively*. Like the chairman of the AIDS committee in Arua diocese told me, “If you love life, you must know your status. I say to people ‘be tested and then you can start planning your life’” (Informal comm. 21 May 2008). In this way, encouraging HIV

testing is not only a method of enrolling clients into the global project to 'save lives with ARV treatment', but it is also connected to the bio-political ambition of reducing HIV prevalence.

The importance of testing for HIV so that 'you can start planning your life' is tied to the otherwise hidden nature of HIV. Even if most Ugandans have relatives who have died of AIDS and are well aware of the common signs and symptoms of HIV and AIDS, the point stressed in HIV/AIDS sensitization and in counseling sessions over and over again is that it is *only* the HIV test, which can reveal the truth about one's sero-status. For example, in a pre-test counselling session in KCCC, Jagwe said to a young woman who had come to be tested; 'there is no other way of knowing than testing the blood. Don't test with your eyes. The judge is the machine.' (Fieldnotes 7 Jan 2009). It is common in Ugandan English to refer to the HIV test as 'the machine' (see also Whyte et al. 2010: 94). That it is only 'the machine who can tell' lucidly reflects the notion that the HIV test is a piece of medical technology, which is believed to be the only method of revealing the biological (and social) truth of ones HIV status, and of another person's HIV status. Counsellors also stress that only the machine can tell, in order to make clear that you cannot see if others are infected with HIV by their physical appearance. As mentioned in chapter 6, counsellors try to promote the notion that it is only if you test together with your partner, you can know the truth about the other person, and plan how to live as a couple.

However, the possibilities and the appeal of following the ethical imperative of testing varies for different people, and especially involving your partner in the process of testing can be a complicated affair, as I will discuss later. While some Ugandans do test for HIV 'just to check', according to my informants, the majority of those who come to clinics like KCCC and Maracha Hospital for testing have some kind of suspicion they are acting upon. In Maracha Hospital, the counsellors and managers have experienced a difference in the percentages testing HIV positive on testing outreaches and in the clinic. Jeremiah contended "those who are coming by themselves voluntary (to the clinic) are those who feel they have not been moving well in life" (Interview 22 May 2009).

Jagwe who volunteered in the AIDS Information Centre (AIC) before coming to work in KCCC had experienced a similar difference in the two clinics with respect to people's motivations to test. In his experience in AIC, a clinic only offering VCT, the majority of those being tested for HIV were 'just checking'. They were people who wanted to go for further studies, to get married or start a relationship together, but "they don't go there, because they are sick". Indeed most of the test results in AIC were negative. In contrast in KCCC, with its clinic and wider support services,

“most people who come here, they know . . . whatever happened to them, so they have something behind them, they know maybe somewhere I could have got the HIV” (Interview 19 Jan 2009). Consequently, in his experience most people coming to KCCC do not receive a positive test result with shock and disbelief, like the people ‘just checking’ in AIC often would.

Most of the clients I interacted with told me they had initially gone for testing, because they were suspecting either their own or their partner’s sexual conduct, and/or were experiencing bodily changes, which could indicate HIV infection. The Ediofe community counsellor Matthias explained that he decided to go with his wife for HIV testing in 2004, because

“I was frequently falling sick, and did not know what, although I was getting my medical treatment . . . there must be something wrong, because I believe this is the right treatment that I used to get, but it used to leave perhaps a year without falling sick, but why it is that this one has become so frequent now?” (Interview 1 May 2009).

Similarly in KCCC, the client Assumpta told me she went for testing in 2001 in response to recurrent illnesses; “I used to have malaria, fever, coughing, especially coughing that would make me very, very weak and it could not stop, so I decided to go there” (Interview 12 Feb 2009). The community workers Josephine and Beatrice went for HIV testing after realising or suspecting that their husbands were HIV positive. Josephine tested for HIV in 2001 a few months after her husband had been tested positive and shortly thereafter died. When she tested she was already convinced that she was HIV positive (and indeed she was).

When going for voluntary counselling and testing in response to some kind of ‘suspicion’, Whyte et al. (nd.) argues that the process is comparable to divination in the way it involves a decision to make a formal inquiry into causes of misfortune by ‘going to ask’ (cf. Whyte 1997). VCT is also comparable to divination in the way that the revelation of an otherwise hidden cause of misfortune engenders a process of reflecting upon past and present relationships, and opens up new possibilities, questions and dilemmas for future actions (Whyte et al nd.).

In VCT, clients are encouraged to use the HIV test to reflect on future actions as a matter ‘planning’. In pre-test sessions, counsellors usually ask the client what he or she plans to do respective of the test result; ‘no matter the result, it will just be a matter of implementing your plan’, Jagwe told the young woman (Fieldnotes 7 Jan 2009). As discussed in chapter 6, when someone tests positive, the KCCC counsellors try to ‘empower’ the person to accept his or her HIV positive status as a new biological and social truth

they need to consider from now on through Positive Living practices. Following Positive Living practices can thus constitute a way of responding to the new truth revealed by the HIV test. But a crucial point is that like other responses to misfortunes, this ‘plan’ may also raise new uncertainties and dilemmas, as this chapter will show (see also Mogensen 2010). And for some, following Positive Living practices and becoming ‘a client’ does not immediately seem like a realistic or acceptable plan for action - like for the young woman Nadine, which I discussed in chapter 6. Her case will be discussed further below.

The uncertainty of testing negative

Apart from the situations where people react in shock and denial to an HIV positive status, testing negative is in some respects a more uncertain result than testing positive. Most of the clinics I have studied use the HIV antibody test. Anti-bodies for HIV may take up to three months to develop after HIV infection, therefore the antibody test may not necessarily give a positive result for someone who has recently been infected with HIV. This is what is known as the window period. Thus, the machine’s capacity to reveal the truth is flawed, since a negative result means that HIV may in fact be hiding and cannot be shown yet.

The young woman that Jagwe counselled tested negative. Apart from the fact that this result meant that she had to consider searching elsewhere for a response to the headaches and breathing problems she had had for several months, Jagwe also emphasised the uncertainty of the negative result to her: ‘Your test may be negative, but yet you were infected yesterday. The testing machines we have here take up to three months to detect it. That’s why we say come back after three months’ (Fieldnotes 7 Jan 2009). Especially in different clinics in Arua Diocese¹³⁷, the counsellors explained the window period to people testing negative in a way, which emphasised continued uncertainty about the person’s true status. In Ocodri Health Centre, a man who had tested negative was told:

‘You do not have HIV virus yet. It does not mean that it is not there. Sometimes, they might be there but inactive, few in number and even not strong enough to fight the white blood cells yet. Therefore, there is need to check again at least three times after every three months’ (Fieldnotes 20 May 2008).

The uncertainty of the negative test result is central to the way counsellors and clients were struggling to make sense and manage HIV discordance, as will be discussed in more detail below.

¹³⁷ In May 2008, I observed pre- and post-test counselling sessions in five different clinics across the Arua diocese (including Maracha Hospital and Ediofe Health Centre).

Becoming a client - a potential for new life chances or a hazardous affair?

With the increasing access to ARV treatment in Uganda, becoming a client in a treatment programme constitutes a more promising way of engaging the uncertainty of living with HIV/AIDS than prior to the scale-up. Becoming a client holds the potential to access not only the life-prolonging medicine, but also to get advice on life-prolonging everyday practices, maybe to get access to social or economic support services, to become part of a community of people living with HIV/AIDS (in post-test clubs or support groups), and for some, to eventually become Ambassadors of Positive Living.

When in pre-test counselling sessions, clients are asked what they will do if they test positive, a standard reply is often 'I will start on treatment', sometimes added with 'and follow the advice of the counsellors'. At times, clients replied with an almost perfect recital of the rules of Positive Living. In a pre-test counselling session in Ocodri Health Centre, a woman replied 'in case I am positive I will hold on to the guidance and counselling given to me already. I will not move out with men in order to spread and also have positive attitude about myself, because I am not going to die tomorrow but can still live longer' (Fieldnotes 20 May 2008). In Ediofe Health Centre, a woman said; 'I will accept and go for these drugs they give to HIV positive, and I will join these groups and then I will feel I'm not alone, 'we're many', and I will feel comforted. I will also stay close to my religion'. (Fieldnotes 15 May 2008).

These replies may reflect that clients merely give the answer they believe is expected of them, but the fact that they so easily repeat Positive Living rules also suggests that following 'the rules' is now established as a well known plan for action for people testing HIV positive in Uganda. Their replies illustrate that it is well established that Positive Living includes 'having a positive attitude', and the spiritual component of 'staying close to my religion'. However, in the context of these rather standard replies, practical and personal difficulties in following the rules are rarely discussed.

Following 'the rules' may both constitute a potential plan for action if the test results are positive, or a possible way of responding to specific symptoms such as recurrent illnesses that do not respond to usual treatments. Another woman in Ediofe Health Centre said that she had come to test because she had been sick on and off without improvement, even though she had been getting treatment, and now she wanted to know her status; 'if I am positive, I can go on treatment and get better' (Fieldnotes 15 May 2008). After an HIV/AIDS sensitization in a market place in Logiri parish, the Arua DFP told me that people thought we had come with

medicine – ‘they wanted medicine, even without being tested’ he claimed (Fieldnotes 18 May 2008). These points illustrate how ARV medicine constitutes a powerful potential for addressing misfortunes. Compared to the situation in the 1990s where an HIV positive result to many seemed like a practical and paralyzing death sentence (cf. Pool, Nyanzi & Whitworth 2001; Mogensen 2010: 63-4; Whyte 1997: 213-9), testing for HIV holds a far greater potential today, because of the possibilities of accessing ARV treatment.

However, my experiences in both Kampala and Arua highlight that the potentiality of becoming a client is experienced differently for people in different positions and in different places in their lives. This is reflected among other things by the apparent differences behind people’s decisions to go for HIV testing: do you test just to check, when signs or suspicions first appear or do you wait until the painful truth of HIV positivity can no longer be avoided? The aspect of having to publicly disclose one’s HIV positive status, or at least be seen in an AIDS clinic, seems central to shaping the potential or risk of becoming a client (see also Whyte et al. 2010: 91-3). In my fieldwork, I had contacts with groups of people in each end of the spectrum, so to speak.

At one end, we can place the successful Ambassadors of Positive Living. Their experiences illustrate that for some becoming a ‘Positive Living star’ can be a promising endeavour, which may bring new popularity and a position of expertise. Apart from the local Positive Living stars, like Beatrice, Josephine and Matthias that I discussed in the previous chapter, there are also national Positive Living stars in Uganda, who have managed to build a national and an international career as Positive Living experts, such as Major Rubaramira, Milly Katana, Dr. Lydia Mungherera and Rev. Canon Gideon Byamugisha¹³⁸. At the other end of the spectrum, we can place Catholic priests and religious brothers and sisters who face a particular difficult task in publicly being known to live with HIV/AIDS. To them becoming a client is a threatening predicament, which is not easily reconciled with existing identities. In my experience, most clients find themselves somewhere in between these extreme positions, reflected by the fact that most client have only partially disclosed their HIV status.

¹³⁸ Major Rubaramira is an army general who has been openly living with HIV for many years. He is the founder and leader of NGEN+. Milly Katana is a well-known AIDS activist who sat on the board of the Global Fund. Dr. Lydia Mungherera was one of the first doctors in Uganda to publicly announce her HIV positive status. She is the founder of Mama’s Club and Uganda Cares. Rev. Canon Gideon Byamagisha was first the African religious leader to openly declare his HIV positive status in 1992. He is the founder of the African Network of Religious Leaders Living with and Personally Affected HIV and AIDS.

Testing and living with HIV/AIDS in secret

In the beginning of 2009, the Arua DFP Phillip Govule, started a special health project for members of the clergy as well as religious brothers and sisters in the diocese. The idea, he explained, was to give them an opportunity to access health services, including HIV testing, in a discrete manner (Informal comm. 23 Feb 2009). On a later occasion, Phillip explained that his concern was that they would not test for HIV unless they were seriously ill. In other words, they would only test when the painful truth of HIV positivity no longer could be avoided. Phillip's concern was therefore that they would come to know their HIV status too late for them to benefit from the life-prolonging potentials of ARV medicine (Informal comm. 14 July 2010).

The primary purpose of the programme was therefore to find ways of giving members of the clergy, and religious brothers and sisters, a safe place to test for HIV. Phillip argued that it was especially their vows to celibacy that were crucial deterrents to them ever publicly announcing an HIV positive status like other religious leaders in Uganda have. A number of Anglican priests in Uganda have come out as HIV positive, but to my knowledge no Catholic priests, brothers or sisters have ever done so. Phillip said; 'It's difficult for people to imagine them as HIV positive; how did you get it, through the Holy Spirit? It means they have broken their vows' (Informal comm. 14 July 2010). Thus, generally, it seems that continued popular perceptions of HIV/AIDS as connected to illicit sex proves a significant barrier for some groups of people to (publicly) becoming a client.

For example, also for the Ediofe counsellor Jacinto, being a catechist appeared to pose a barrier to testing for HIV. In the interview, he emphasised his role in encouraging people living with HIV/AIDS to 'come out of their hiding', but yet he did not count himself among those who may need to come out. Wrongly assuming that all of the Ediofe community counsellors were HIV positive, I straightforwardly asked him 'when did you learn your status?' to which he replied 'I have not come for voluntary testing'. I apologized, explaining I had assumed they were all HIV positive, and he explained that there were three of them who were not HIV positive. I asked him whether he might test one day, and at first he said 'anyway, I will try to check whether...'. I pushed him a bit more, by saying: 'I just wonder when you encourage others to test, why you have not gone yourself?' Then he replied: 'As I'm working as a catechist, I know myself, I have been faithful to myself, so I think for me it's not important to have this test' (Non-recorded interview w. translation 30 Apr 2009).

In the special health programme for the diocese's clerics, Phillip gathered a number of Catholic doctors and HIV counsellors to come once a week to

offer the service in the Bishop's private premises¹³⁹. One of those involved in the programme was Emily who is the counselling coordinator in the AIDS programme in Arua hospital. She is also a prominent Catholic, as she heads the Family Life Desk (a desk in the diocese's Pastoral department) with her husband. In her capacity as both a devoted Catholic and an HIV counsellor, she has established contact with a number of priests and sisters living with HIV/AIDS. One day she took me on a home visit to a Catholic priest living with HIV/AIDS. This was a home visit very different from those I was used to observing. There were not much of the usual discussions about whether the client was taking the drugs as prescribed, no counting pills and no reminders of 'the rules' or the client's next appointment date. Below are some of the notes I took after the visit:

I went on a home visit today with Emily from AHAP. We visited a priest staying in x parish. He had contracted meningitis during the meningitis epidemic in West Nile in January, which has affected his hearing and sight, so that he can neither hear nor see and hardly talk . . . Emily told me after the visit that he had previously been admitted in Maracha Hospital for one month, and he was tested from there and 'put on their programme'. When he was discharged from Maracha, he moved here to x parish, which is where he is originally from. He came to Arua Hospital when he got meningitis with a referral letter from Maracha.

His mother is taking care of him, but 'she doesn't know'. Emily had requested the financial officer in the diocese for someone to take care of him, and they got an elderly woman, which they will give some 'appreciation'.

When we visited the priest in the Fathers' House, his mother, the woman and another priest were present. Emily took a long time to try to get him to sit up to take his medicine. But first she explained and discussed with the two women about the medicine: which ones he was supposed to take and how many.

She also visited him yesterday and she saw a small improvement today. According to the other priest his hearing has improved and when Emily flicked her finger in front of his eyes he kind of reacted. She finally managed to give him the pill by crushing it and mixing it with juice. She then gave him a cup of tea and before that took his arm and made the Sign of the Cross with his arm. She asked me to hold him a bit, touch his arm and shoulders, because '*he needs to feel that someone cares*'. When we concluded the visit, the other priest said a prayer.

The other priest said to Emily that the elderly woman the diocese had found was good, because she had managed such a case previously (Fieldnotes 26 Feb 2009).

During the visit I was not introduced as a PhD student on research, but as someone working with Sr. Paula in Ediofe Health Centre, and I did not take any notes during the visit. The way Emily and the other priest tactfully

¹³⁹ However, in July 2010 I learnt that Phillip had never succeeding in finding funding for the programme and it had more or less stopped. But he said: 'Even if the health clinic has not been taking place the last 2 months, they still come to me, I deal with them confidentially' (Informal comm. 14 July 2010).

handled the visit and the whole matter is similar to reports of how relatives in the 1990s in Uganda would take care of sick members of their family, suspecting they probably had AIDS, but never discussing it openly (e.g. Whyte 1997: 214-5; Mogensen 2010: 64-9). The difference of course being that Emily, the caretaker and the other priest did know about his status, and that biomedical treatment (septrin) meant specifically to address his HIV infection was given to him. If this priest recovers and begins a more normalised life on ARV treatment, he would most likely have to do so under great discretion, but I suspect that Emily and the diocese would attempt to help him do so.

On a more general level, many informants pointed out that people in higher or public positions were usually more concerned with publicly admitting to be living with HIV/AIDS. Thus, a key difference seems to be that for those who have more face to save, publicly announcing your HIV positive status can be a threat (see also Whyte et. al. 2004: 23). While for others who may not have much status to lose, disclosing may instead be a way to access resources, like Beatrice who got access to school fees support by disclosing her status (see also Whyte et al. 2010: 91).

This difference might explain the observation made by many informants that fewer men than women were coming for HIV testing and accessing treatment. In Maracha Hospital, Joyce claimed that women ‘are more free’ and ‘want to know their status’, while men are afraid of testing because of stigma (Interview 12 May 2009). Though, the interns, Simon and Victoria argued that it seemed men were more reluctant to come to the clinic than for the testing itself, because when they went on testing outreaches many men, often outweighing the women, would come to get tested (Interview 12 May 2009). This could suggest that men may be willing to get tested ‘just to check’, but more reluctant to get tested when they are actually ‘suspecting’. This was Matthias experience;

“normally when the woman discovers that she has now been affected, she gets concerned and definitely she will say, I better save my life for my children here, she will go for treatment and so on, so the man still try to hide it, they try to, they think there is an imaginary way of . . . that it is not there . . . They’re trying to avoid it, that’s why, because they don’t want to be seen, they would not want to become to see themselves perhaps getting the treatment, going to the hospital there, to that particular ward where they normally, when they see you going that way, they will wonder ‘eh, this one also’” (Interview 1 May 2009).

Thus, men’s testing patterns also indicate how the benefits and risks of publicly ‘becoming a client’ can be structured by positions of social and moral authority. The literature on masculinities and health point out that the ‘signifiers of masculinity’ used by men to negotiate social power and status may help to undermine their health. Thus, in attempting to enact

hegemonic masculinity, to most Ugandan men ‘becoming a client’ can be a possible threat to their status as a breadwinner and household head, or to have many sexual partners and father children (Wyrod 2011; see also Simpson 2010).

Testing positive, but not ready to ‘become a client’

Apart from the fact that social status may structure the potentially or risk of becoming a client, different life situations can also be a significant factor in shaping the potentials of becoming a client. One example is the young girl Nadine discussed in chapter 6. During the pre-test session, Nadine explained to Olga that she was dating a man, who was Born-Again like her, and that she had decided to come and test because he wanted to go and introduce her. She had come to test alone, because, as she said, her brother-in-law had recommended it to her – ‘It’s good for you to go for testing alone, then you know your results and go together’. When Olga asked the standard question about which result she expected, Nadine replied that she expected the results to be negative, and considering her reactions to the positive test result, it seems she was not one those ‘suspecting’. However, her decision to come alone may be connected to a small seed of suspicion and especially the fact that though her and her boyfriend were abstaining, she had had a sexual partner before him.

When Nadine was told her HIV positive results, her immediate life plans seemed shattered, one of the first things she said was: ‘now what will I say to my boyfriend? I’ve only had sexual relations with one person. He went to South Africa’. She later explained that as Born-Again Christians, her and her current boyfriend had not been having sex, and in the 2 years they had been dating, he had ‘never said anything that he wanted to have sex’. First, it seems she was wondering how to explain her HIV positive status to her boyfriend, when their relationship was premised on a mutual, moral commitment not to practice sex before marriage. But more than that, she seemed distressed that her imminent life plans of marriage were in ruins. As mentioned in chapter 6, her parents had already planned the introduction. Nadine plans for marriage, it turned out, were also tied into her broader social situation. She explained that she had recently been fired from her job as a shopkeeper, and then she subsequently had been evicted from the small house she was renting, and ‘that man has been taking care of me’.

In this situation, testing HIV positive was not immediately an opportunity for Nadine to begin to manage her life according to this new biological and social truth. Rather it was disastrous news possibly putting an end to all her plans and posing a threat to her social situation. Despite Olga’s efforts to use her entire counselling repertoire, providing pastoral counselling and

giving her own testimony, it did not seem to comfort her much. Olga encouraged Nadine to go to her church ‘and interact with people’, but Nadine did not seem to consider her church a place to find support to deal with this news, she said ‘there is no one I can share with. They will start hating me’. After the session my assistant Norah declared that she is also a Born-Again Christian and said to Nadine ‘you’re going to be my friend’. Thereby she gave her an opportunity for support and understanding from a fellow Born-Again. The possible bond between her and Norah was further tied when it turned out that not only was Nadine a Musoga like Norah, they were also from the same village just outside Jinja. Nadine exchanged phone numbers with both Norah and Olga. But neither of them has ever heard from her again (Fieldnotes 7 Jan 2009).

In conclusion, becoming a client constitutes an uneven process structured by questions of identity, social status, specific life situations, as well as access to treatment and other resources, which may constitute possible approaches to address misfortunes.

Being a client – negotiating the rules in everyday lives

Becoming a client holds a potential for *some* people living with HIV/AIDS to follow a new plan for action, which includes accessing treatment and getting advice on life-prolonging everyday practices. However, to follow this plan and to realise its life-prolonging potentials, the plan’s requirements must be worked out in the context of the home and within kinship relations.

This section analyses different ways clients attempt to realise the life-prolonging potentials of Positive Living and taking ARV medicine. In order to highlight the new uncertainties and dilemmas that following ‘the rules’ may pose for people living with HIV/AIDS, I focus on those clients who in various ways struggle to benefit from these potentials, and those who critique, negotiate, or find other paths holding greater potentials than following ‘the rules’. Because of the emphasis in counselling and home visiting on whether clients ‘perform well’, I also consider the possible space such practices leave for clients to tactically appear as though they follow the rules, when they are in fact struggling to do so. First, I analyse how clients negotiate the sexual responsibility required of people living with HIV/AIDS. Then, I analyse how ‘the rules’ of ARV treatment is negotiated with everyday concerns of survival, responsibilities towards family and kin and other ‘hopes for the future’.

Negotiating sexual responsibility and managing relationships

As the above discussions have touched upon one of the central challenges to ‘become a client’ is the way that a HIV positive status reflects back on

past sexual relationships and also poses new dilemmas for future sexual relationships. As discussed in chapter 6, counsellors often approached questions of clients' sexual behaviour from a moralistic standpoint as something possibly suspect. This phenomenon is both connected to the possible threat HIV positive people's sexuality pose to the general population and to the success 'saving lives with ARV treatment'.

In this section, I first consider how clients attempt to negotiate a kind of sexual ethics in this moralised context, and then I analyse how clients attempt to negotiate the sexual responsibility required of them with wishes or expectations to have children. Thereafter, I consider the challenges of coming to test and living with HIV 'as a couple', which includes an analysis of the complications of managing and making sense of HIV discordance.

Sexual ethics as a client

A number of the clients, especially the KCCC community workers who were also HIV positive, talked much about *other* clients who were not practicing sexual responsibility, while highlighting their own sexual responsibility. For example, Beatrice emphasised to me in the interview that she thanked God that "ever since I knew I was infected I never got involved with any other man", even if she was "looking beautiful". But in the interview, she also talked about other clients who found it difficult to disclose to their partners and therefore were taking the drugs in secret; "you see that these people are promiscuous, they are spreading the disease so much". Later in the interview, Beatrice expanded on the challenge women taking ARV treatment are faced with in terms of practising sexual responsibility:

"as you know, men always admire women, if I can tell you how many men want to befriend me, others wanted even to wed me, you tell them the truth but they refuse to take it, because depending on the way you look that you're deceiving them, you just don't want to have a relationship with them, because we look good even better than those who say they are normal . . . that is why so many people are dying, they just go on having relationships, then you see that this disease continue spreading, if I was not patient, following the rules of the doctors, following the rules of the counsellors, and also befriend them and tell them whatever happens in my life, if I get worried or anything which makes me worried I run to them they listen to me, I also come back when I'm ok, that is the situation" (Interview w. translation 28 Jan 2009).

While Beatrice maintained that other clients go on having relationships and continue to spread the virus, she emphasised her own ability to resist temptations and conduct herself according to the ethics of protecting others from infection. She connected her success in following the rules to making use of the confessional technology of counselling.

However, since the counsellors experienced that few clients were willing to confess about their sexual and reproductive matters, it may indicate that the majority of clients try to negotiate a kind of sexual ethics as a client in different ways. According to my experiences in the three Catholic organisations, the careful ethical negotiation of their sexuality that clients must engage in is reflected by two distinct phenomena: a tendency for clients to partner with another HIV positive person, and a tendency of trying to *appear* to counsellors and community workers as though they are following 'the rules' of sexual responsibility, in situations where they do not follow the rules to the letter.

Counsellors in both Maracha's AIDS clinic and in KCCC emphasised how AIDS clinics and post-test clubs at times function almost like a dating service. Joyce explained that some clients 'marry among themselves'; they 'come to learn about each other from here, when they come to collect the drugs' (Fieldnotes 17 March 2009). In KCCC, Damian said that clients would often ask him "have you heard of any man who wants a woman that is positive . . . can you help me and they get me a man who's positive, who's like me, other than infecting others?". He was not comfortable with just referring such a woman to any random male client he knew of, but encouraged clients who made such requests to join the post-test club in order to "get to know them more . . . because when you are in a support group, they do activities, that's how they get close to each other . . . and by getting closer to each other they know whom they can go with" (Interview 19 Jan 2009).

The second phenomena is that in several counselling sessions it seemed clear that clients were trying to tactically avoid having to confess about their sexual relations, insisting or implying instead that they were not having sex at all. In one of Joyce's consultations in Maracha a man and a woman had come for their appointment with their newborn child. During the session, they discussed whether the baby would be breastfed and when to test the baby for HIV. After the woman had left the room to be examined by a doctor, Joyce asked the man 'when you sleep at home as a husband and wife, what do use, condoms or what?', the man promptly replied 'we've not been having sex'. Joyce, laughing, asked 'how did you get this baby if you don't have sex?' The man said nothing. Joyce continued to counsel him to be careful and to go to another health centre for advice on family planning (Fieldnotes 12 May 2009). 'We've not been having sex' seem to come as a standard, rehearsed reply from the man, even in this situation where it obviously made little sense (unless the man was implying that his wife had the child with another man). This example illustrate how the emphasis on generalised instructions and checking 'performance

indicators' in counselling may leave some space for clients to *appear* as though they follow the rules of sexual conduct.

Having children?

One of the factors, which make it difficult for clients to follow 'the rules' of sexual conduct, is how to negotiate these rules with desires, wishes or expectations to have children. As mentioned in chapter 6, it was a common perception among both counsellors and clients that they are not really 'allowed' to have children. However, as experienced in Nigeria, having children may constitute a principal method for people living with HIV/AIDS to confirm that they have returned to a normalised life (Smith & Mbakwem 2010). In Uganda, evidence also suggests that women receiving ARV treatment express increased wishes to have children (Maier et al. 2009).

These dilemmas may explain why the counsellors often experienced that clients were not honest about their sexual conduct and especially wishes or plans to have children. Joyce said she had often counselled female clients who were claiming not to have sex at all, only to discover later that they were pregnant (Fieldnotes 5 Mar 2009). Some of the counsellors in KCCC had a few experiences with clients who discussed their reproductive wishes with them. Anthony argued that a wish to have children was the main reason why some discordant couples continued to have 'live sex' even if the counsellors had carefully explained to them the risk of doing so. In his experience, this was the case especially for couples who did not yet had children or only had one child. Generally talking about clients who wanted to have children, Anthony mentioned the case of one woman he had recently counselled:

"I was counselling a certain lady, she's positive registered here, but she refused to disclose to the husband, then I was discussing with her how to go about disclosing, but she was telling me, me I know my husband, I know his behaviour, either he might run away from me, or he might beat me, and then I miss the support, and then when I was discussing wit this lady, now what do you when you meet with your husband, do you share about condomizing, say I cannot even mention a condom to him, because we have only one child and I need another child, you see those are the challenges. . . she's not ready to disclose to the husband, and one of her reasons was that the man might chase her away and she is has been dependent on this man" (Interview 2 Feb 2009).

This case illustrates how as a woman, you might have to negotiate the expectations of your husband and his relatives to bear children, while dealing with difficult questions of whether and how to disclose to a husband, you are dependent upon. Anthony mentioned that the woman was actually suspecting that her husband was also HIV positive, but she was still afraid of the possible implications of disclosing her status to him. This

example illustrates how women's supposed right to make 'informed decisions' about both reproduction and methods to 'remain with your virus' is complicated by 'the social issues' that often keeps Ugandan women dependent on their husband or casual partners for survival (cf. Richey 2011).

The challenges of disclosing to and bringing your partner(s) for testing

The practice of coming together with your partner to test for HIV, which counsellors promote as the only way to know the truth about your partner, and therefore the best way to 'plan' how to live as a couple, is not an easy path to follow for most clients. Mathias appear as the rare good example in this regard, having decided to come with his wife for HIV testing in response to recurrent illnesses. He thus exemplifies the kind of 'responsible man' who takes his wife for HIV testing figuring on one of the posters hanging in the AIDS clinic in Maracha Hospital. In all three Catholic organisations, the stories of women who were struggling in various ways to disclose to their husbands or who were struggling to encourage their husband to test were many. In Joyce's experience disclosure was a huge challenge for women;

'if they disclose to their husband, there will be chaos, quarrelling, 'you were the one who brought it'. So many of them don't disclose to their husband. For those who do disclose to their husbands, the husbands take their own time to come' (Informal. comm. 24 March 2009).

However, the challenge may also apply the other way around. With the KCCC community worker Thaddeus we visited a man who was struggling to disclose his status to his wife. His previous wife had died in 2004, presumably of AIDS. But when he married his new wife he was not yet sure of his status, he said, and now he found it difficult to disclose to her:

'I'm trying to tell her, but there are some things you don't tell people directly. I've not disclosed to her. What I try to do is what they told me to do, I use condoms and she's on family planning, for her to avoid to get pregnant' (Fieldnotes 13 Jan 2009).

But again, his statements seemed somewhat inconsistent, since he had and the new wife had a 2-year-old baby together, whose HIV status he wanted to go and check without her knowledge. The community worker Thaddeus did not probe into the matter though, but just thanked the man for looking after his wife.

During the few home visits I participated in, in Maracha Hospital, the complications of disclosing to your partner(s) were a common theme. On one home visit, we paid a visit to a couple in Otravu (a small trading centre ca. 5 km. east of the hospital). During the visit, a number of relatives were present and Joyce involved them in the discussion. According to the man's

brother, the couple was not ‘cooperating well’, because the woman had become ‘very annoyed’ with the husband when he revealed his was HIV positive. She had said ‘I’m already dead, you have given me the HIV’. When Joyce tried to probe into this conflict, the man and woman gave conflicting stories:

The woman said: *When he came back from the hospital, I asked him, you went for blood exam, what did they find? He told me he was not given the result, but he was requested to bring the wife and children for blood exam.*

The man objected and said: *I told her I tested positive and when she went to test, she was also found positive and she became annoyed to me. So our relationships is not ok. Sometimes I cook for myself, she cooks for herself privately. Even my neighbours know about it. (Fieldnotes 29 Apr 2009).*

Another example more broadly illustrates how living with HIV/AIDS ‘as a couple’ is not necessarily a harmonious experience of ‘planning’ how to live together. The example also demonstrates how conflicts over who ‘has brought the disease’ might be embedded in complicated kinship relations. We visited a couple staying in Kimiru parish. When we first arrived only the woman was present and Joyce started to talk to her:

Joyce: *you told me you separated with your husband, what is the issue?*

Woman: *because of family wrangles, the husband is not helping the family, we can even stay for 2 days without his support. And when I don’t go for casual work, we stay hungry. When I ask him to contribute, to help the family he becomes annoyed. This time he stays with his mother.*

...

Joyce: *Your husband had gone to pick drugs from Maracha. He told me all his belongings were stolen, is it true?*

Woman: *they only stole his bicycle and from that time up to now, he’s angry with me. Also I called my relatives to speak to the relatives of my husband. And the relatives of my husband told those of mine that he is already dead and they blame me for that. He also takes alcohol and he smokes, and because he’s angry to me, I can’t now advise him (Fieldnotes 25 March 2009).*

Joyce then explained to me and my assistant Jimmy that ‘this quarrel began long time ago. Her mother-in-law, sister-in-law was taking bad about her, that she’s the one who brought the virus to their son. Yet he is the one who brought’. Joyce explained the she and the other counsellor who used to work in the AIDS clinic had counselled them together, and afterwards ‘they were staying together ok’, but now it had been a long time since she had visited them. Joyce then asked the women to fetch her husband and when he came, Joyce started to discuss the matter with him.

Joyce: *how is home?*

Man: *home is just fair, cooperation is not up to date*

Joyce: *What did I tell you when I come here?*

Man: *the problem is whenever we have a problem, she takes it to the relatives. They come and insult me. I just lost interest in staying here, because her relatives were insulting me.*

Woman: *what about the children, do you help them?*

Man: *what you're saying is false, you're making false accusations on me.*

Joyce: *the reason I have come today is not to make you quarrel again. After the first problem, you were ok . . . for all this you're giving trouble to your children.* (Fieldnotes 25 March 2009).

The couple continued to quarrel for a very long time, and eventually, Joyce resigned and said: 'Here, I'm going to stop. In summary, I urge you to send the children to school. When you get something of food, you give to them'. After this visit, Joyce was rather frustrated and said 'for cases like this, you can keep counselling, but it doesn't help, they keep quarrelling' (Fieldnotes 25 March 2009).

Managing and making sense of HIV discordance

In situations of HIV discordance, the way that an HIV positive status reflects back on past relationships, and pose dilemmas for future relationships, is even more complicated. HIV discordance may imply that the positive partner has been unfaithful, and for the future of the relationship difficult decisions must be made. As mentioned in chapter 6, in KCCC discordant couples are referred to partner organisations that specialise in the matter (and can provide them with condoms). But both the KCCC counsellors and Joyce in Maracha, also try to counsel the couples with an interest in encouraging them to stay together, given them the option of using condoms or abstaining from sex to prevent sero-conversion. As indicated above, managing these choices are not necessarily simple, especially if the couple wants to have children.

However, what further complicates the matter is the challenge of understanding how HIV discordance is actually possible. In all the three Catholic organisations, clients, counsellors, community workers and HIV/AIDS sensitisers were struggling to make sense of HIV discordance. In KCCC, we went on a home visit to woman who was the negative part of a discordant couple. She told us that they were among the first cases of discordance in Uganda, and that they had lived as a discordant couple for 13 years. They had been involved in research projects in the Virus Research Institute in Entebbe for many years, and she was tested every three months. She explained, however, that she had only begun to use condoms in 2002, because before that she had doubted her status as negative, she was convinced that when her husband was positive, she also had to be (Fieldnotes 17 June 2008).

A common perception in both Kampala and Arua was that the HIV negative partner might still be in the window period, i.e. that the virus is somehow hiding and failing to show yet. This perception is connected to the uncertainty of the negative test result that I discussed above. The possible paradoxical consequences of this uncertainty might be that the HIV negative partner eventually becomes positive, if condom use seems pointless anyway. On another Maracha home visit in Otravu, the uncertainty of a negative test result when your partner is HIV positive, and the possible ramifications of this uncertainty, was vividly demonstrated.

On our way to the homestead, Joyce introduced the clients we were going to visit as ‘a discordant couple, the woman is still testing negative’. However it turned out that notion of ‘discordant couple’ did not quite capture the whole situation, since the man had had three wives. One of them had left him, only the second wife had tested and continued to test negative, while the first wife had refused to test. During the first part of the visit, Joyce discussed with the man about his health and side-effects of the septrin, he was taking. When Joyce asked him about how his relationships with his wives, he said: ‘our relationship is not all that fine’. He explained that with his first wife, he had ‘separated with sexually’ and that he had advised her to go testing, but she had refused. He wanted Joyce to talk to her and convince her to test, but Joyce said that you cannot force someone to test. Joyce then asked about the second wife:

Joyce: *sexually how do you relate?*

Man: *I use condoms, I don't have unprotected sex and not regularly.*

Joyce: *I heard sometimes your second wife take your drugs and take them, is she doing it now?*

Man: *I stopped her from doing that. I told her these are my drugs, they're strong, don't do it.*

Later the second wife joined us and Joyce said to her: *I've come to see you, tell me how you're staying at home, do you have any problem?*

Woman: *Yes, even though I tested 6 times, I'm convinced I have the virus.*

Joyce: *what result was given to you?*

Woman: *negative, but they also told me maybe the virus has not yet shown itself. So I believe, I'm living with the virus. I have general body weakness. I've been doing business, but now if I stand in the sun for long, I can just faint, I don't know if it's typhoid or not, I have not gone for medical attention. Generally my health has deteriorated.*

Joyce: *whenever you fall sick, I advise you to go to the hospital. Anybody who doesn't have the virus can also get sick, it's not always the HIV that make you sick. Your only problem is the denial of your result. (Fieldnotes 29 Apr 2009).*

While Joyce found that the second wife was denying her test result, from the wife's perspective it seems she was merely following the logic the intern counsellors in Maracha Hospital was explaining to her; she might still be in the window period. And since she had been having 'general body weakness', it seemed quite possible that she had the virus, but that it had just not yet shown itself. However, because she continued to test negative, she could not access the life-prolonging medicine, her husband was taking, which is perhaps why she had decided to take some of his pills instead. As discussed in chapter 6, Joyce did usually not distinguish between septrin and ARV medicine in the rules that they come with and in the effects they have, which explains why the second wife might find her husband's septrin pills so interesting.

Negotiating the rules of ARV treatment in everyday lives

With the increasing availability of ARV treatment in Uganda, accessing the treatment constitutes one of the central attractions to 'become a client' in an AIDS programme today. ARV treatment promises to prolong life beyond what was achievable previously with only Positive Living practices. But like the rules of sexual conduct, the rules of the ARV treatment must also be negotiated in everyday lives.

As discussed in chapter 6, the techniques used by counsellors in KCCC and the AIDS clinic in Maracha Hospital to encourage clients to follow the rules of ARV treatment help to constitute the medicine as extremely potent. If you follow the rules well the medicine can be no less than 'miraculous', but if you do not follow the rules well, the medicine can in turn be poisonous or even deadly. Consequently, while ARV treatment constitutes a possibility to regain life and continue to live for long with HIV, clients are often 'well educated' about the fact that realising the treatment's potentials requires that you follow the rules: adhere well to the drugs and continue to do so for the rest of your life, come on time for your appointments, eat well, do not worry and overwork yourself, do not drink or smoke, do not have unprotected sex etc.

I begin this section with discussing the way some clients, who were 'ready' to start ARV treatment reflected on their ability to follow the rules and the potential harmful effects of the medicine if they failed to do so. Then I consider how clients who had been taking ARV treatment for some time reflected on the daily 'homework', which was required to realise the medicine's 'miraculous' potentials. Thereafter, I analyse a number of cases of clients who in various ways were struggling to realise the medicine's potentials and to follow the rules, or who tried to negotiate the rules with possibly conflicting strategies of 'Positive Living' or other life projects.

To start ARV treatment or not

In both KCCC and the AIDS clinic in Maracha Hospital, counsellors and doctors are involved in assessing whether clients are eligible in medical and social terms for starting ARV treatment. However, clients also make their own reflections. In KCCC, a young Muslim man whom I call Waseem reflected on the long-term commitment of ARV treatment:

“At first I feared, I said no, because it’s a life-time thing, you can’t just go, because doctors have told you, it scared me and doctors told me, if you’re scared, you’ve got the right to first have to like build up your mind” (Interview 29 Jan 2009).

After a few weeks, he decided though that he had to respond to his worsening health and would have to live with ‘the rules’ that came with medicine; “but since my body was . . . like going down, and I said no, my CD4s are going down every now and then . . . let me go” (Interview 29 Jan 2009).

The young woman Rose, mentioned in chapter 8, was also concerned about beginning ARV treatment. Rose was already taking TB medication, but had been sent to Jagwe’s ART education session in order to begin ARV treatment. At the end of the group session, Rose voiced her concerns to Jagwe. Afterwards, Jagwe narrated her concerns to Norah and me:

The sister-in-law brought her here when she was very sick, she stayed in Kawempe. They sold the land and moved to Kasangati, now she stays there with her brother. But his children mistreat her, she tried to make her brother help, but he just said, what can I do? Now those children threw her property out. So she was forced to shift to her own house, which is not yet complete. She’s no longer working, she used to work in Owino¹⁴⁰, but stopped because of the prolonged illness. Then had a capital drainage. And she is still weak, she wonders how will I feed until I am well enough to work for myself? (Fieldnotes 20 Jan 2009).

As mentioned in chapter 8, a few days later I went with Esther and the community health worker Proscovia to visit Rose and her brother. We first visited Rose in her new house in Kasangati, which was still under construction. The roof was not quite complete and one of the two rooms was filled with bricks. Rose again voiced her concerns to Esther:

Me I have nothing to eat. I told Mr. (Jagwe), he was going to talk to my brother. My brother brought me here, they started abusing me. I can’t work because I have problems with my legs. My brother treats me like a housemaid, when I told them, his wife was very annoyed, they threw my things out and now I’m here. I can even take 2 days without eating. It is these people who build who brought food, I cook it and we eat together. That situation was not good, because I was worried. But where I was before, I had neighbours who would help me. That is what is

¹⁴⁰ Owino is a huge market area in the centre of Kampala.

affecting my life. If I could only improve, so I can start working (Fieldnotes 22 Jan 2009).

We all later went to her brother's house a few kilometres away, and Esther tried to encourage him to help Rose with food until she improved and could start working for herself, as discussed in chapter 8. About 2 weeks later, Norah met Rose in the clinic when Rose had come for her appointment, and she told Norah that her brother had brought food for her only once, since Esther's intervention. Consequently, for Rose, starting ARV treatment constituted a new beginning of uncertain survival, constrained by complicated family relations and a precarious living situation.

Miraculous recovery requires careful management

Going on home visits, I met many clients who spoke with great gratitude of the 'miraculous' transformation the ARV treatment had effected in their bodies and their lives. On a Maracha home visit, we visited a man with two wives, who stayed in Oleba (about 10 km. north of the hospital). When we entered their house, the man said to me in English:

My life is because of these people, since I got this infection in 1999, they have given me treatment and advice. My whole family is infected, even the youngest child, who is in P6. If the counsellor was not here, we would have died. When all us fell sick in this home, the counsellor came all the way from Maracha to visit us in this home. . . We went to the doctor immediately, we were advised not to miss the drugs. I have many empty containers of ARVs.

While Joyce was talking to the two wives, the man went to get a large plastic bag full of empty ARV pill containers, which he proudly showed to me (Fieldnotes 5 March 2009).

This man was thus showing his gratitude to Joyce and to me (often assumed to be a representative of 'the donors') for the medicine and the counselling, which had saved their lives. In KCCC, we visited a woman, who said 'I didn't know I would survive up to 2009, but I'm grateful to the funders . . . I started in 2006, but I felt so sick in 2005, I didn't even know if I would survive. I was just waiting for my day to go' (Fieldnotes 8 Jan 2009). These recurrent themes of gratitude possibly reflect how the clients were playing the part of 'therapeutic citizen' or maybe showing respect to 'their patrons'.

The stories of miraculous transformation often included references to the first critical couples of week, when survival seemed uncertain. When I interviewed Waseem he had been on ARV treatment for about one and a half month and he had overcome the first critical couple of weeks, but was still experiencing some of 'the initial reactions' to the ARV medicine:

I've got a lot of challenges, that's why I wanted even to call auntie (Nankya), so I get dizziness, after dizziness you get fever, after fever you get these dreams I

started saying a-ah . . . and even the dreams haven't stopped up to now, they haven't, so I'm just getting used, but with the dizziness, it has gone. . . I always get, like I get broken like I have no joints ahh, the head is loaded, but with time I will, I think I will get better and I just wanted to ask whether it's part of the disease

Matilda: it is . . . it clears with time (Interview 29 Jan 2009).

These kinds of experiences with the first couple of weeks and months on ARV treatment were common among the clients I interacted with. They illustrate one of the ways in which the potency of the ARV medicine manifested itself.

Apart from overcoming the critical start-up phase, the stories of successful transformation were often characterised by references to how the client had learnt how to adjust the rules, and the potency, of the treatment with practical, everyday concerns. A woman staying in Kagoma explained how she had changed the time for taking the medicine to 8 a.m. and 8 p.m.:

'I used not to have appetite, and then when I took the medicine, I got problems. I used to swallow at 10 a.m., some time I would oversleep and reach to 11 a.m., that's why I changed, so I take them just before sleeping. When my children sees it is time, they'll bring my drugs and a glass of water' (Fieldnotes 13 Jan 2009).

One of the clients I interviewed in KCCC was the primary school teacher Patricia. When asked how she had been doing since started the treatment, she replied:

I've not had any problems, except if I don't eat on time. I can even fail to move, like if I'm in town and don't take lunch, I can even fail to move. I take the drugs at bedtime and then I sleep well, unlike before I could stay a whole night without sleeping' (Non-recorded interview 15 Jan 2009).

Like Patricia, many clients had experienced the dizziness and other ill effects, which came with taking the ARV medicine without having eaten. Many therefore tried to adjust the time for taking the drugs to suit practicalities around eating, as best they could, since meal times are often not that predictable in Uganda. In her first two weeks taking ARV treatment, Assumpta had experienced the way the drugs required new considerations of what and when to eat:

"sometimes these drugs they, you found out that you get diarrhoea, feel dizzy, as you are working. . . you are the bread-earner of the family, so many problems we face with these drugs, maybe there should be accompanied with some of the assistance, the patients, as you give them, you find somebody cannot afford to buy what yogurt, milk what, it may not, I don't think it would treat well yeah. . . . I have taking them for only 2 weeks, I feel dizzy and weak, because, but I try, me I move always with water, I always take water, yeah to dissolve the medicine" (Interview 12 Feb 2009).

Assumpta felt she was managing the dietary requirements of the ARV medicine relatively well, but she wondered how other clients who were not as well off as her, would manage. Later in the interview she recommended that KCCC included some kind of food assistance, to help clients manage the nutritional requirements. This was a kind of assistance she had seen practiced in the AIDS clinic in Rubaga Hospital (a Catholic hospital), where she was a client before she transferred to KCCC.

Viola – the ARVs not doing their ‘magic’

In KCCC, the client Viola provides an example of the ARV medicine failing to ‘do its magic’, because of her challenges in following the rules, most importantly the rule of having a balanced diet. Her situation illustrates how the nutrition that is required to realise the treatment’s potentials hinges on one’s wider social situation, especially now that food supplements are no longer provided, which otherwise could constitute a form of fallback support for clients like her.

I first met Viola when I went with the community health worker Baseke on home visits in Nansana, a peri-urban area situated about 12-15 km. north of Kampala. I returned to visit Viola again about two weeks later and during this visit I conducted a loosely structured interview with her. Viola had been a client in KCCC for many years, since around 1999 she believed. She had developed TB about three years back and had been taking TB medication. She had been taking ARV treatment now for almost a year. However, her immediate physical appearance suggested that she was not doing particularly well. During the first visit, one of the first things she said was:

I don’t have capital, that’s one of my problems. This child is no longer going to school. My biggest problem is lack of feeding, poor feeding. Also lack of school fees. I fell sick when there were only these 2 in the house. Taking drugs, when you’ve not eaten is very bad. I feel I’m oppressed, I don’t have food – my husband deserted me.

Viola’s breathing seemed strained, and when Norah asked her about it, she replied: *‘I’m anaemic. I saw Dr. John and he told me that I’m very anaemic. I asked: Do I need blood transfusion? Dr. John said you need to eat well . . . you wait. They told me to eat things like eggs, but I cannot afford* (Fieldnotes 8 Jan 2009).

Viola was now alone in the house with two small children, a boy, who was 2-3 years old, and her 8-year-old daughter, who was the one no longer going to school. The little boy had been born with TB and been admitted for 6 months in Mulago Hospital¹⁴¹ after his birth. He looked to be quite malnourished. Viola’s husband had ‘deserted her’ after realizing that she

¹⁴¹ The national referral hospital.

was HIV positive, while he was negative. The husband had moved back to Kamwokya, where they had lived before, with the couple's three other, older children. Viola had recently been so ill that she had been admitted to hospital; her oldest son had arranged for a car from KCCC to come and transport her to the hospital. This son was also one of her only sources of support now that she was alone in Nansana with the two small children. The son would come on the weekends with food (e.g. rice and posho) and help her to fetch water, because she was now too weak to fetch water.

It seemed quite evident that her anaemia was a consequence of not getting enough to eat while taking ARV medicine. As she got weaker because of the anaemia, it made it even more difficult for her to do some kind of work, which could enable her to get food for herself and her children. Now that her husband had left, she seemed to have very few sources of support nearby. For the last three years, she had not been able to work, first because of the TB, now because of general weakness and anaemia. However, she used to have her own business:

I used to trade in charcoal, sugar cane, banana leaves. I used to trade in all those things, I used to bring charcoal from the village and sell it to people here, even matooke. For three years, I've not been working. I stayed in Kamwokya - I stayed there one year without working and now I have spent two years here without working (Fieldnotes 23 Jan 2009).

Viola was adamant that she needed 'capital', so she could start working again (i.e. to start a small business) to truly address her precarious situation. She said: 'at least if I work I can solve my problems. This issue of begging people, people get tired, I'm burdening my son and there's nothing I can do' (Fieldnotes 8 Jan 2009). Viola was experiencing that people around her were 'getting tired' of supporting her, and she was also concerned about 'burdening her son' who had just finished school (he had gone to KCCC's vocational school). Thus, Viola's survival had for some time been highly dependent on accessing help and support through family relations. But because the support she was able to access was limited and uncertain, she felt that getting her own income would be a more certain plan. It was therefore not surprising that during my visits to her, she also made appeals to me for help, especially to get 'some capital'. Quite unusually I did offer her some (minor) assistance. But on the second visit it did not seem that the 20,000 shillings¹⁴² I had given her was enough capital to start selling charcoal, as she hoped to do. However, she had kept the 20,000 and was looking for some way to invest the money in something that would generate more money, so that she would not just 'eat' the 20,000 shillings (Fieldnotes 23 Jan 2009).

¹⁴² This is equivalent to 10 US dollars. In the Kampala area, a sack of charcoal cost around 25,000 shillings at this time.

In the interview, it became clear that she had known her HIV positive status for several years without having disclosed this to her husband. She had tested positive when she was pregnant with her now 8-year-old daughter, and at that time she knew that the husband had previously tested negative. When he subsequently developed a rash, she encouraged him to test for HIV again, but he refused. She did not disclose to him when she started the ARV treatment either. However, he eventually found out, and though he refused to test for HIV again, he went away, knowing ‘I’m infected and for him, he is negative’, she said (Fieldnotes 23 Jan 2009). Though I failed to get into depths to the matter during the interview¹⁴³, given the precarious social situation Viola now faced after her husband had left her, it is not surprising why she would have been reluctant to disclose her HIV status to him.

During the second visit, we learned that she had gotten some medicine for the anaemia. However, she still seemed to find her situation desperate, so desperate that she now wanted to send one or both of her children away: ‘I love my children, but this one if I could give him away. I’m trying to look for peace’, she said at first. Later during the interview, she explained:

‘The food is a problem and also my child, feeding these children, if you have what to eat, then you don’t worry.... If the children find food in the cupboard....that is one of the reasons I want to take them away’. (Fieldnotes 23 Jan 2009).

Viola’s situation illustrates that it can be quite difficult ‘not to worry’ as you are supposed to in order to protect your CD4 cells, when you are struggling to follow another central rule: getting enough to eat. Viola was not only struggling to get enough to eat for herself, but also her children, and this situation was only adding to her worries. Sending them away seemed like a temporary solution to her challenges. However, the CHW Baseke discouraged her, arguing that she would later regret having sent her children away - ‘I’m suggesting that you can stay with them and God will help you survive’ (Fieldnotes 23 Jan 2009). Thus in the face of Viola’s immense social problems, Baseke, like a number of other counsellors and community workers in KCCC, encouraged her to ‘lift her problems up to God’.

About 2 weeks later I met Viola in the clinic in KCCC and she looked to have improved a bit, and she said she was doing good. But being too weak to do much work and with extremely limited options to access support through her family relations, Viola’s continued survival seemed a highly uncertain affair.

¹⁴³ Viola was obviously not so comfortable discussing these matters with her daughter in the room, and in fact the daughter was sent away when I started asking questions about her status and whether she disclosed to her husband.

Chasing food aid in DR Congo

The clients in KCCC and the AIDS clinic in Maracha Hospital are meticulously educated about the need to ‘eat well’ in order to realise the ARV medicine’s life-prolonging potentials. But additionally if they, like Viola, fail to eat well they will often experience in their bodies, how poor nutrition make them fail to realise the medicine’s potentials, at times making them even more ill.

My research in Maracha Hospital took place during a time of severe food shortages. It was ‘the hunger season’ and prices on food were higher than usual, because the trade into Southern Sudan was pushing up the prices on most commodities in the region. In this context, the rule of ‘eating well’ and the rule of ‘not overworking’ could be contradicting, as indicated earlier. On a home visit to a couple staying close by the hospital, Joyce asked the couple how they were doing. They replied:

Woman: *Because of too much work, I feel general body pain.*

Man: *Because I’m now working in the garden, I also feel general body pain.*

Joyce: *Yes, I can see that you’re working too hard.*

Man: *I’ve resorted to working very hard simply because there’s no money to pay for casual work. I’m unable to hire someone to work for me, even I’m unable to buy milk for this child. Even I pay school fees for two children.*

Joyce: *Besides all this, you at least give your body chance to rest (Fieldnotes 25 March 2009).*

In this context, it was not surprising that news of possible food assistance for people living with HIV/AIDS attracted a lot of attention among the clients in Maracha Hospital. From the start of my fieldwork there, I heard the rumour that ‘somebody is looking for those who are positive; a *muzungu* in Ombokolo, to be supplied with food’ (Fieldnotes 5 March 2009). Omboloko is a small town in DR Congo just across the border. Some of the rumours of food aid in DR Congo seemed highly exaggerated. On one of the clinic days, Joyce did not come to work because she was attending a funeral. While I was waiting in the clinic, with the clients who had come for their appointment, the clients discussed the food support in DRC. The man we had visited in Oleba told us that last time this NGO in DRC was giving out food support they had given; ‘1 sack of posho, 1 bassin of beans, 1 bar of soap, 1 full basin of rice, half kilo of salt and 3 litres of cooking oil’ to each person. Another woman explained that there was actually a food distribution today; ‘today that programme has collided with coming for drugs, so I have chosen to come for drugs’. The clients

said they did not know which organisation or where ‘the muzungus who give this help’ come from (Fieldnotes 3 Apr 2009)¹⁴⁴.

Though this woman had chosen to follow the rules and come for her appointment on time, other clients ended up missing their appointments because they were trying to access this food support. A few weeks later, an elderly man came into the clinic limping. He explained to Joyce that his feet had swelled after walking back and forth to Congo¹⁴⁵ in hopes of accessing food support from the ‘NGO giving food’. Joyce checked his file and found out that he had missed his appointment by one week. She scolded him for missing his appointment and for chasing this elusive food aid, which had not even materialised; ‘Now, you went to Congo for food, but I learnt you have come back without any food’ Joyce said to him. The man explained: ‘In fact, we were deceived. They called us for a meeting in order to elect leaders amongst ourselves, they knew when they said go for food, many will go’ (Fieldnotes 28 Apr 2009). Joyce generally thought the clients were rather foolish to chase this food aid at the expense of following the rules. In her view sacrificing their health for lofty promises. However, in the face of Maracha Hospital’s extremely limited treatment and care services, the prospects of being able to access food aid by virtue of HIV positivity seemed an opportunity not to be missed for many clients.

Fatuma – it used to be easy

In chapter 7, I argued that in all the three Catholic organisations there is a dominant self-responsibilisation discourse, which places the burden for addressing social barriers to ARV treatment success on the clients and their families. Viola’s example demonstrated how the client’s ability to access assistance through kinship relations consequently become central for realising the life-prolonging potentials of ARV treatment. In this context, ‘eating well’ is a central challenge, but generally to follow ‘the rules’ clients must rely on the social relations they have at hand.

Another client from KCCC struggling to follow the rules will provide an example. This client is an elderly woman whom I call Fatuma. Like Viola, Fatuma seemed to have overstretched her family and kin’s ability and willingness to offer support. Fatuma lives in the small town of Manyangwa

¹⁴⁴ At the end of my fieldwork, I managed to locate this organisation and went a brief visit to their office in the border town of Aru. The organisation is called Institut Panafricain de Santé Communautaire et Medecine Tropicale (IPASC). IPASC provides care and support to people living with HIV/AIDS, which includes food support, home visits and a weekly transport to Arua Hospital for treatment. The food support is provided by WFP Congo (informal comm. with IPASC executive director 18 May 2009).

¹⁴⁵ Maracha Hospital is situated less than 10 km. from the border to DR Congo. Some of the hospital’s catchment area is practically right by the border.

in Wakiso district, about 25 km. north of Kampala. She lives in a small two-roomed house by the main road, with two adult daughters and their children. I first visited her when I went with the CHW Proscovia on home visits in the border region between Wakiso and Luweero districts. Having access to my car as a means of transport, Proscovia took us to visit clients she rarely had a chance to visit, because of the distance.

On our first visit, Fatuma had just returned from Mulago Hospital; she had been admitted with cough and fever, and was in a drip. Fatuma told us that she had missed some doses because of vomiting. Proscovia found Fatuma's pill jars and checked her appointment date and said to me and Norah: 'her appointment was yesterday and she has only 2 doses left, and her containers are disorganised after being in Mulago'. Fatuma asked me whether her daughter could come with us in the car back to Kamwokya to pick the drugs, and then the daughter would return on her own means. I agreed. Proscovia told me that it was the third time Fatuma had been admitted. She explained that when clients are admitted in Mulago or elsewhere, the CHWs come and visit them, and follow up. It seemed that Fatuma and her daughters didn't know, because they were not informed (otherwise Proscovia could have brought her new dose of drug to her in the hospital). It seemed later, though, that the problem had been that her daughters had refused to inform KCCC.

At the end of the visit, Fatuma changed her mind and said to me: 'I will go with you to Kamwokya, I can see that my daughter is low'. So Fatuma came along with us on the drive back to Kamwokya. (Fieldnotes 19 Dec 2008).

I returned to visit Fatuma on the day when Esther had come along to visit Rose in Kasangati. Since we had discussed Fatuma's problems with adherence, transport and her 'social support system' on the way there, Esther took charge of the visit and began to counsel Fatuma. Below are excerpts of my notes from their conversation:

Esther: *How are you?*

Fatuma: *I wanted to come and they check my CD4, because I'm weak, when I came they didn't check it, they have taken long. I was admitted.... My medicine got finished.*

Esther: *Do you have the card?* (the adherence card)

Fatuma: *I don't know where the card is. I can't find it. I don't have medicine. They gave me the blue one and the white one for one month.*

Esther: *When are you supposed to come back?*

Fatuma: *There are some who fell on the ground that I didn't swallow.*

Esther asks Fatuma to go and get those pills that fell on the ground.

....

Esther: *You were supposed to come back on 16th.*

Fatuma: *Transport is a problem. Then I found counsellor Patrick, because he is my counsellor. . . He was my first counsellor. I told him this morning. He said he would bring for me.*

Esther: *Do you have other people who help you?*

Fatuma: *It seems they're tired of me.....The daughters are also married, they have their families, I talk about it with Kasamba and this one (the CHW) if it's possible that we make an office here, because there are so many people here.*

Esther: *We shall remind him when we go, we will raise our voice and take to higher places. . . . You talked about the problem of transport.*

Fatuma: *From here, I get off from Wandegeya, then I board Bukoto- Kamwokya- Ntinda. Then coming back, I must have something like 5,000 or 6,000 thousand shillings.*

Esther: *How about feeding? How about the people you stay with?*

Fatuma: *They eat posho, beans... it's just gambling*

Esther: *. . .What have you done to see that you get something to survive?*

Fatuma: *Depending on the energy I have, I can do small businesses, like frying chips. But I don't have capital..... school fees have increased... my children have become stubborn, they don't get satisfied, when they find a boda man, they get chapatti... and they end up pregnant. Their father died a long time ago. He died in 2006. He was also suffering from the disease. He was working in Makerere, those people who said they would support us, we don't see them (Fieldnotes 22 Jan 2009).*

Towards the end of the visit, Esther tried to conclude their discussions by saying: 'Depending on what we discussed, the most important thing is taking the drugs. Do you know what it means to your life?' She also encouraged Fatuma to find someone to help her with some 'capital' so that she could start a small business. But Fatuma kept talking about the challenges clients residing in the area were facing. Esther reassured her again that she would take up the issue of opening some kind of outreach in the area, with the doctors and management. Fatuma then said:

It used to be easy. I think most of you are new, they used to give house rent, they gave sewing machines, but people never gave them back. Kasamba knows about these things. I came to Kamwokya in 1999, most people died when I was there. (Fieldnotes 22 Jan 2009).

Back in the car, Esther explained to us that Patrick Kasamba used to manage the food programme when it was still running, but now he had been transferred to the mental health department. When he worked with the food programme he really got to know the clients and some clients still 'sing his song', she said. Apparently Patrick Kasamba had used to deliver

medicines and food supplements to Fatuma's home. Fatuma seemed not to fully understand that this arrangement was no longer in place. She connected Patrick to a different time in KCCC, a time when it used be easy and KCCC provided things like rent, sewing machines and food. Proscovia and Esther, she found, did not understand how KCCC used to provide care and support; they seemed instead to part of this new era, when it was no longer so easy.

Fatuma's experiences vividly reflect the changes to the holistic care support structure in KCCC and how, presently, successful management of the rules of ARV treatment requires that you can 'work for yourself'. Being weak, in and out of hospital, a bit confused and having few avenues of support now that 'her people were getting tired' of helping her, it was not easy for Fatuma to independently follow the rules of ARV treatment, without relying on KCCC for assistance as she previously had. Particularly, Fatuma's challenges in finding the money and energy to transport herself to KCCC for her monthly appointments posed a challenge for her to adhere well to the ARV medicine, in turn only worsening her health and her ability to work for herself. Notably, Fatuma had only received ARV drugs for 1 month the time I drove her to the clinic; probably she was required to come for re-fill quite regularly because of a poor adherence record. As discussed in chapter 6, adjusting the doses was one way of rewarding or punishing clients for good or bad 'performance' in both KCCC and Maracha Hospital. Fatuma's experiences illustrate how such policies may constitute a vicious circle for those struggling to follow the rules.

The challenges of missing your appointment because of transport problems was also relevant for the Maracha clients as indicated in chapter 7. Though the distance to the clinic was generally shorter for the Maracha clients than those living rather far away from KCCC, transport options are fewer in Maracha county. Clients who were too ill to walk to the clinic, would often be stuck at home while their conditions worsened, unless they were able to get a family member or neighbour to pick drugs on their behalf, or unless Joyce discovered it in time and also was able to access fuel to go with the hospital vehicle to visit them.

Fatuma's experiences also crystallize the paradox that arises in KCCC from the fact that despite official policies that ART clients must reside within Kampala district, they tend to accept ART clients who reside quite far away. At the same time, they continue to demand that such clients come regularly for appointments as a method to ensure adherence to the medicine. In response to this paradox, KCCC was during the time of my research in fact involved in setting up replicate organisations in 4 different locations in districts neighbouring Kampala. I am not certain how seriously Esther tried to take up the issue of opening some kind of out-reach clinic in

the area, as Fatuma kept asking for. During the visit, Esther seemed rather to be concerned with working on changing Fatuma's perception of the situation; instead of looking at KCCC for assistance, Esther was trying to make Fatuma see opportunities for sustaining herself, now that 'her people' was not of much help. In other words, Esther was trying to 'responsibilise' Fatuma from being a passive recipient to being active and self-sustaining.

The Saved preacher – it is not the church who makes me sick, it's being idle

The two final examples of this discussion will focus on clients who were trying to negotiate the rules of ARV treatment with possibly conflicting life projects or strategies of 'Positive Living'.

The first example is a man living in Kyebando, a slum area close to Kamwokya, called David. David was a member of a local Pentecostal church, called Rock of Ages, and he also preached on the street. The home visit to him was characterised by the suspicions most counsellors and community workers in KCCC had towards clients who are members of Pentecostal churches – who are 'Born-Again' or 'Saved'. In KCCC, there were persistent rumours and stories about Saved clients who were told by their pastors to stop taking ARV medicine, because the Holy Spirit would heal them instead. The proliferation of such rumours probably have to be seen in the light of how KCCC as a Catholic organisation were positioned to the threat of the growing popularity of Pentecostal churches¹⁴⁶. Most of the community health workers (the majority being Catholics, and the rest Anglicans and a few Muslims) were suspicious about the possible negative influence of Pentecostal churches on their project to ensure ARV treatment adherence. Therefore, as I learnt after this home visit, the fact that my assistant Norah was 'Saved' was a potential problem that Norah and I had to carefully manage during the fieldwork in KCCC. A few days after we had visited David, we were approached by Mr. Bisase who seemed concerned about the possible influence of Norah's participation in home visits on Saved clients. He said to us: 'you know we have these Saved clients; we encourage them very much to take the drugs. It is not that they have to give up their praying, but they can take the drugs and still continue with their praying' (Fieldnotes 16 Dec 2008).

We visited David, when we went with Doris on home visits in Kyebando. Doris was a devoted Anglican, who was often the one saying the closing prayers in HBC team meetings. Before we visited David, Doris had told us

¹⁴⁶ According to Gusman (2010), though the rumours of Pentecostal pastors discouraging people from taking ARV medicine are quite widespread in Kampala, it is to his knowledge only a few of the Pentecostal churches in Kampala who in fact preach such messages.

that she wanted to talk to him, because he used to preach on the street, and now she had heard that he had started preaching on the street again. David was both taking ‘mental health drugs’ and ARV medicine, and he had previously been admitted to the mental hospital three times. The doctors in KCCC were concerned about the effects of standing all day in the sun, preaching on the street, for his mental and general health. When we entered his house Doris first asked: *How is church?* And David replied: *I’m still praying.* Doris then started a long speech, which not only targeted his street preaching, but also generally discouraged him to go to the Rock of Ages church:

I wanted you to come to the clinic, we pray yes, but inside the Saved church. That affects you, if you’re not well, you can be affected because these Saved shout so much. They’re just singing and shouting until late. Stop going to that church, you will be affected. You can end up going back to the mental hospital. At KCCC, they asked us are you living in a place with a lot of noise? . . . Too much noise is not good for the mentally ill. You can read the bible, read the word of God and share with your church. . . . The Saved churches always shout a lot.

To this, Norah objected and said: *No it is not so. I’m also Saved.*

Doris and Norah then discussed which church Norah went to. Afterwards, Doris asked David about the medicine for his mental problems, and he explained that when he went for overnight praying, he did not take the drugs for mental problems, because they made him sleepy. Doris cautioned: ‘You can’t treat with the word of God alone’. But David insisted that: ‘The church does not stop me from swallowing the medicine, it is me who decide not to take, only when I go for overnight’. Later he explained that he took his ARV medicine well, it was only the drugs for mental problems, which he did not take when he went for overnight prayers.

Daniel explained that he used to be a teacher and he had tried to go back to teaching, but it was too straining for him. He had to go to work very early in the morning and would come back late, and then ‘the pupils would make me shout’. The mental hospital had written to the school requesting them to find simpler work for him, but they had not replied. David said:

’So, I’m here. I don’t have any income-generating activity. So you find most times, I’m just praying . . . I tried to go back to teaching, but it’s straining. But in church, you can just sit, not participate and you pass the day, like on Fridays we start at 3 p.m. and go to 6 in the morning. The problem is staying alone in the house without nothing to do. It is not the church who makes me sick, it’s being idle. If I stay home, idle, my body will feel sick, even if I have fever or flue, when I go to church, I come back when I’m delivered’.

His mother now got involved in the discussion and said: *The Rock of Ages church look after him well, they show him love.* David also explained: *they (KCCC) used to give us porridge and oil. So now we’re badly off. In my church there is always food, and they give 700 to women to buy milk.* (Fieldnotes 12 Dec 2008).

David was in some respects following the rules well: he was taking the ARV medicine correctly. But he was at odds with other rules; he was not always taking his mental health drugs correctly, he had begun to preach on the street again, and generally his involvement in a Pentecostal church was, from the perspectives of the community workers and doctors, a potential threat to his adherence to the ARV medicine. However, in a sense David had developed his own Positive Living strategies: he had found a way 'not to worry', not to sit at home being idle and feeling redundant. In the church he also found a sense of community and belonging, which 'delivered' him from worries and minor illnesses, in much the same way, it is assumed post-test club and support groups can do. Additionally, in the face of KCCC's discontinued food support, his church could also offer a form of support KCCC could no longer offer. David seemed to insist on realising the potentials of taking ARV medicine and Positive Living practices in his own way, insisting that being part of the Rock of Ages church and being a preacher was central for his physical and mental well-being.

Assumpta – being the provider

I first met the KCCC client Assumpta when she came for counselling to receive results from a recent CD4 count. During this session Assumpta was given the CD4 count result, which determined that it was now time for her to begin ARV treatment. I interviewed her around 1 month later, when she had been on ARV treatment for two weeks. Assumpta appeared ready and willing to follow the rules of ARVs well, and having a reasonably well-paid office clerk job, she also seemed to be in a relatively good position to do so. However, Assumpta's considerations around how to practically follow the rules were significantly structured by her position as 'the breadwinner' in her family.

During the interview, Assumpta explained that she was a single parent taking care of four children, her own two daughters, her deceased sister's son and her deceased brother's daughter. She explained she had separated from her husband several years ago, and that she was the one who had educated her children all the way from primary school to university. When Norah and I first met her, and asked her permission to observe the counselling session, she was concerned about her HIV positive status being publicised. She said 'I don't want to see my name in the newspaper and loose my job'. Norah and I assured her several times, that I would ensure her anonymity (Fieldnotes 15 Dec 2008). It was clear that Assumpta had not publicly disclosed her status, because she was afraid of losing her job.

Assumpta tried in different ways to reconcile being a client, and now also taking ARV medicine, with her position as the breadwinner of the family. As mentioned above, after beginning ARV treatment, she found that the

side effects sometimes posed a challenge for her to effectively do her job. In connection with her job, she had recently completed a bachelor degree in her field and she had just been for the graduation¹⁴⁷. She was supposed to start ARV treatment before Christmas, but she had asked her counsellor and CHW to wait until after her graduation; “I never wanted to take drugs, before I went for graduation . . . I never knew the reaction, can make you very weak and you can’t reach the school” (Interview 12 Feb 2009). Though Assumpta said during the counselling session that she felt she was getting weaker and was suspecting it was time to start on ARVs (Fieldnotes 15 Dec 2008), she also had other ‘hopes for the future’, which starting ARV treatment had to be negotiated with.

During the counselling session, Daniel informed Assumpta that from now on, community workers from KCCC would come to visit her in her home, and therefore she needed to disclose to at least one member of her household. Assumpta wondered how she could combine the home visits with having to go to work every day. But she agreed to the arrangement then (Fieldnotes 15 Dec 2008). During the interview, she talked about her first experiences with receiving community health workers in her home: “sometimes they don’t keep appointment, yeah they can say now we are coming on Monday and you sit there, yet I work in a public place, when I’m not there . . . people of the office start calling me, where are you, where are you?” However, she now tried to work out an agreement with her CHW to make appointments for the visits.

Assumpta explained how she had now disclosed to one of her daughters, in accordance with the requirements of being an ART client. She had not previously disclosed to her children or anyone else in her household. She contended, however, that her daughters had been suspecting it (Interview 12 Feb 2009). Assumpta’s situation reflects how partial disclosure has to be negotiated with the requirements to receive home visits. Assumpta decided to disclose to one of her daughters and introduced the daughter to the community health workers, but a number of other clients in KCCC had not disclosed to anyone in their household. Some of them managed to work out an agreement with their community health worker to receive ‘home visits’ in their workplace or come to KCCC instead.

All in all, Assumpta was compared to Viola and Fatuma in a relatively better position to realise the potentials of ARV treatment. However, the requirements of taking the drug at a particular time, eating and drinking certain things at the right time, and receiving community workers in her home had to be reconciled with her status as the provider, holding a public

¹⁴⁷ Some details are withheld here to ensure her anonymity.

job, without which her ability to realise the potentials of the ARVs would much more difficult.

Chapter conclusion

This chapter has illustrated how the greater availability of ARV treatment has significantly altered the potentials of ‘becoming a client’ in AIDS treatment programmes in Uganda. The access to ARV treatment constitutes a potentially promising way of engaging the uncertainty of living with HIV/AIDS. But like other responses to misfortunes, taking ARV medicine and following Positive Living advice engenders new dilemmas and uncertainties. For one, the prospect of living, more or less openly, with HIV/AIDS continues to be structured by questions of identity, social position and by specific life situations. This is especially because of the way the new social and biological truth revealed by testing HIV positive reflects back on past relationships and pose new difficult questions for future relationships. This phenomenon was most acutely illustrated by the immense difficulties for Catholic members of the clergy to ‘become a client’.

Becoming a client to access ARV treatment is a response to misfortune, which requires one to follow very specific rules. The chapter has provided an indicative analysis of the different ways clients try to realise the potentials of Positive Living and ARV treatment in their own lives. One point was that when working out possible conflicting agendas around sexual and reproductive conduct, some clients tactically appear to follow the rules of sexual conduct, rather than confessing their sexual and reproductive desires to counsellors and community workers.

I have pointed to how realising the life-prolonging potentials of ARV medicine is embedded in social relations and structured by social differences. Now that the burden for addressing social barriers to ARV treatment success is increasingly placed on the shoulders of clients and their families, most clients greatly rely on the kind of support and assistance they can access through kinship relations. There are few, though, who found other avenues of support in communities, such as Pentecostal churches (in Kampala) and post-test clubs (like the ‘Ambassadors of Positive Living’ discussed in chapter 8).

Generally, the analysis indicates that for the clients whose avenues for support are limited, strained or uncertain, taking ARV treatment constitutes a remarkably uncertain path of survival. Therefore, I argue that, practices of ‘treatment, care and support’, like those pursued by KCCC, Maracha Hospital’s AIDS clinic and the HBC programme coordinated by Ediofe Health Centre, may contribute to the production of new uncertainties of

living with HIV/AIDS, and new inequalities between those who can successfully follow the rules of Positive Living and ARV treatment and those who struggle to do so.

10. Conclusion

Concluding on this dissertation, I return to the research questions outlined in the introduction: *how is ‘treatment, care and support’ for people living with HIV/AIDS practised in KCCC, Maracha hospital’s AIDS clinic and the Ediofe HBC programme, and what effects do these practices have on how people living with HIV/AIDS attempt to realise the life-prolonging potentials of ARV medicine and ‘Positive Living’ in their own lives?*

I summarise the dissertation’s answers to these questions in three parts. First, I conclude on the differences between the three Catholic organisations in terms of how and the conditions under which ‘treatment, care and support’ is practised. Secondly, I conclude on what I have gained by studying the ARV treatment scale-up in Catholic organisations through the lens of ‘holistic care’, and I also consider what these analyses illustrate about how ‘global AIDS treatment’ is currently practised and debated. Finally, I conclude on how these practices of ‘treatment, care and support’ produce new life-prolonging potentials for people living with HIV/AIDS, as well as new uncertainties and inequalities.

Three different Catholic organisations in Kampala and Arua

Having analysed the different ways ‘treatment, care and support’ is practised in the three Catholic organisations, I have illustrated some of the inequalities of the Ugandan treatment and care landscape and three different Catholic forms of involvement with ‘global AIDS treatment’.

Kamwokya Christian Caring Community in Kampala Archdiocese reflects the potentials of fostering lay activism as a method to develop community-based responses to social problems. However, the experience of KCCC over the last two decades reflects the professionalisation and ‘projectification’ that usually follows from accessing international funding (see e.g. Gifford 2009). Growing into a professional NGO has reconfigured the pastoral ministry character of KCCC in a way, which has challenged the integration of spiritual, material and social healing. This is a trend, which the introduction of ARV treatment has only reinforced. The pharmaceutical dominance produced by ARV rationalities and techniques is now sidelining both the pastoral care orientation of their work and their efforts at being a ‘welfare office’ for Kamwokya.

The experience of KCCC is, however, somewhat unique to the Kampala setting. And despite the current limitations to KCCC’ services, compared to

the AIDS clinic in Maracha Hospital, KCCC can offer a more technologically advanced treatment and support service. KCCC provides better and more varied ARV medicines, opportunities to do CD 4 cell counts and viral load counts, they have a higher paid and more specialised counselling team and more systematic home visits etc. Despite clients' limited access to KCCC' social support services and the discontinuation of food support, some limited forms of assistance can be offered to some clients to help them follow 'the rules' of ARV treatment.

In contrast, the AIDS clinic in Maracha Hospital in Arua Diocese provides an extremely limited ARV treatment service, which to the hospital managers constitutes more of a problem than a solution to the community's health problems. The clinic exemplifies the challenges of providing ARV treatment in rural health facilities without much outside funding. As a Catholic hospital, Maracha Hospital has opportunities to access resources through various Catholic networks and by charging a user fee, but the hospital is also in some respects more resource constrained than government facilities, as reflected by the staff's lower pay. In this resource constrained clinic, following 'the rules' of ARV treatment is to an even greater extent than in KCCC a disciplining and individualising endeavour.

In the Arua context where 'outside funding' is patchier than in Kampala, the home-based care programme coordinated by Ediofe Health Centre reflects a way for European missionaries to engage a few resources from their own network to nurture community capacities for self-help. Through local Catholic Church networks and providing basic care for people living with HIV/AIDS, the health centre has been able to mobilise volunteers to provide care and support services rather independently. In relation to neo-liberal development rationalities, the programme seems like a perfect example of a community-based project, which harnesses community capacities while relying on very little outside funding. However, apart from the fact that the programme is quite reliant on the donations from the Italian in-charge, the programme seems to cast the volunteers as local patrons rather than fostering self-reliant families and communities.

The experiences from all the three Catholic organisations indicate that as donors have expanded the funding for *treatment*, the responsibility for *care* and *support* has been increasingly placed on the shoulders of individuals, families and 'communities'.

AIDS treatment and 'holistic care'

The analyses of counselling and home visiting have illustrated that the counsellors and community workers in the three Catholic organisations predominantly attempt to discipline and educate people living with HIV/AIDS to follow 'the rules' of ARV treatment and Positive Living. As part of this form of government, the organisations focus on finding ways to foster self-reliant clients, families and 'communities' who responsibly address any social or economic barriers to following these rules.

It is by analysing these practices of government through the lens of 'holistic care' that the reconfigurations around treatment, care and support taking place in the context of the ARV treatment-scale up have become clearer.

I have pursued the analysis of 'holistic HIV/AIDS care' from two interrelated emic viewpoints. From a Catholic perspective on integrating material, social and spiritual healing in HIV/AIDS care and as the more programmatic question of ensuring prolonged life for people living with HIV/AIDS by targeting not only medical aspects of human existence.

With these two interrelated viewpoints I have been able to point to how Catholic organisations' engagement in treatment and care programmes can contribute to the reconfiguration of pastoral and confessional practices towards psychological techniques of self-transformation. I have illustrated how the scale-up of ARV treatment instils a pharmaceutical bio-political dominance, which sidelines the pastoral care orientation of 'healing' and more broadly reorients ethical subject formation towards following 'the rules' of ARV treatment and Positive Living. In KCCC, we can trace a historical shift in key ethical orientations: from helping people living with HIV/AIDS to *die with dignity* to helping them to *live with rules*.

The pharmaceutical dominance has also sidetracked the material component of holistic care. In the context of the ARV treatment scale-up, the need for targeting social, economic and emotional aspects of living with HIV/AIDS is, in the organisations and among their donors, still considered highly relevant for achieving good treatment outcomes as well as preventing further spread of HIV/AIDS. However, programmes that target social and economic aspects of living with HIV/AIDS are in the first place unevenly distributed in the Ugandan aid landscape. Secondly, in line with neo-liberal development rationalities there are great concerns among the organisations and their donors with providing such services in ways, which may only produce passive dependency. This is a concern, which also resonates with local questioning of special entitlements to people living with HIV/AIDS.

In this context, counselling and home visiting become methods for targeting the responsibilities of individuals and families to become self-sustaining and address such needs with their own means. It is remarkable though that even this constrained 'holistic care' perspective is also constantly at odds with the pressure to perform 'lives saved' in the Catholic organisations. At times, both counselling and home visiting appear to become forums for ARV treatment adherence disciplining and surveillance more than anything else. The ARV medicine has, in effect, become a new powerful authority that structures the government of clients' self-government.

My analysis resonate with those who argue that 'global AIDS treatment' offers only a degraded form of 'global belonging' to people living with HIV/AIDS through its highly medicalised and individualised approach to address the suffering of AIDS (Kalofonos 2008). My analysis illustrate that large-scale ARV treatment programmes not only obscures the political and economic conditions of suffering (Ibid.), they also potentially sideline Catholic, pastoral care approaches to address suffering. This point illustrates how becoming involved in projects to provide ARV treatment can have far-reaching consequences for religious organisations.

Living with rules: new potentials, uncertainties and inequalities

The larger question one might ask is if it is not better to 'live with rules' than to 'die with dignity'? I do not aim to provide a simple yes or no answer to this question. The pastoral ministry approach and following the rules of ARV treatment constitute two different, but potentially equally problematic ways of working out what constitutes 'the good life' in the context of HIV/AIDS. I have tried to demonstrate that for people living with HIV/AIDS the greater availability of ARV treatment in Uganda has certainly provided new opportunities and potentials, but that these potentials also come with new dilemmas and uncertainties.

First, despite the greater availability of ARV treatment, the prospects of living, more or less openly, with HIV/AIDS continue to be structured by questions of identity, social position and by specific life situations. This is especially because of the way the new social and biological truth revealed by testing HIV positive reflects back on past relationships and pose new difficult questions for future relationships. The divergent ways in which people decide to get tested for HIV and to become a 'client' reflect an uneven seepage of medical technology and that despite the dominant forms of government I have identified, these governmental practices do not produce the same effects for everyone.

Secondly, those who become a client in a treatment programme find themselves being on a new path of uncertain survival (Meinert et al. 2009).

The partial and uneven ways that the global project of ‘saving lives with ARV treatment’ targets the suffering of AIDS is reflected in the uncertainties and inequalities faced by people living with HIV/AIDS, when trying to realise the medicine’s potentials. Their access to different kinds of ARV medicines and to other care and support services is, among other things, dependent upon location, shifting donor priorities and one’s ability to perform well as a client.

Because the burden for addressing social barriers to ARV treatment is increasingly placed on the shoulders of clients, their families and ‘communities’, realising the life-prolonging potentials of ARV treatment and ‘Positive Living’ must primarily be worked out in the context of the home and within family and kinship relations. To follow the rules of ARV treatment, most clients therefore greatly rely on the kind of support and assistance they can access through kinship relations. For the clients whose avenues for support are limited, strained or uncertain, taking ARV treatment constitutes a remarkably uncertain path of survival.

Consequently, practices of ‘treatment, care and support’, such as those pursued by KCCC, Maracha Hospital’s AIDS clinic and the home-based care programme coordinated by Ediofe Health Centre, may contribute to the production of new uncertainties of living with HIV/AIDS, and new inequalities between those who can successfully follow the rules of Positive Living and ARV treatment and those who struggle to do so.

My conclusion is thus that the massive allocation of resources for ARV treatment in Sub-Saharan Africa provides a partial potential to prolong life, which produces new social inequalities, by committing ARV patients to follow a meticulous self-government regime. For Catholic organisations involved in the ARV treatment scale-up, we can, in this connection, trace how promoting individual responsible self-government is replacing ethical questions of how to ensure human dignity in times of adversity with spiritual and material assistance.

Appendices

Appendix 1: Overview of the three Catholic organisations

Kamwokya Christian Caring Community (Kampala Archdiocese)	
Type of organisation	Faith-based NGO Started as Catholic lay volunteer initiative (rooted in Small Christian Communities)
Scope of operation	Kampala District
Initiated in	1987
NGO registration	1994
ARV treatment provision	Since 2004
Employees	About 140 full-time
Clients	Over 5,000
‘ARV clients’	Around 1,500
Services offered	Clinic: ARV medicine Prophylactic medicines Voluntary Counselling and Testing On-going counselling CD 4 cell count, viral load and other diagnostic technologies
	Home-based care programme
	Child Welfare department
	Credit & Savings Society
	Community Mental Health
	Youth centre (sports activities and Life Skills seminars)
	Post-test club
Funding sources	PEPFAR
	Scottish Catholic International Aid Fund (SCIAF)
	Caritas Swiss/Luxemburg
	Raskob Foundation for Catholic Activities
	International Association of Voluntary Services (AVSI)
	American Jewish World Service
	COOPI

	Basic Needs (UK)
	Better Way Foundation
	Insieme Si Puo' (and others....)
<i>Key informants</i>	Counsellors previously trained as pastoral workers: Damian, Anthony and Charles Counsellor in charge of 'ART enrolment': Jagwe Community work coordinator: Christine Namukala Home-based care coordinator: Nabeel Bisase HIV + community workers: Beatrice and Cecilia

Maracha Hospital AIDS clinic (Arua Diocese)	
Type of organisation	Clinic in Catholic hospital
Scope of operation	Maracha county (Nyadri District)
Initiated in	2005 (part of TB ward) 2007 moved to a separate clinic
Employees	1 nurse-counsellor (+ doctor on call)
Volunteers	4 interns
Clients	100-120
'ARV clients'	60-70
Services offered	ARV medicine Prophylactic medicines Voluntary Counselling and Testing On-going counselling Prevention of Mother to Child Transmission (Home-based care)
Funding sources	Government ARV programme AIDS Information Centre
Previous funding sources	PSI Uganda Programme for Human and Holistic Development project (USAID)
<i>Key informants</i>	Nurse-counsellor: Joyce Hospital director: Dr. Austin Community work coordinator: Jeremiah

Home-based care programme coordinated by Ediofe Health Centre (Arua Diocese)	
Type of organisation	Volunteer programme coordinated by Catholic health centre III
Scope of operation	Ayivu county (Arua District)
Initiated in	2004
Volunteers	23 currently active, majority are people living with HIV/AIDS
Clients	Not clear, each volunteer has around 20-30 clients that they visit at home
Services offered	Home-based care
	HIV/AIDS sensitisations
Present funding sources	Donations by health centre in-charge (Italian Comboni Sister)
Previous funding sources	2004: AIDS Integrated Model District Programme (USAID) 2005: Rotary Club, Trento, Italy
<i>Key informants</i>	Coordinator: Jimmy Ariko Volunteer community counsellors: Matthias and Josephine

Appendix 2: Overview of research activities***Overview of research activities completed March-June 2008*****Mapping process March-May 2008**

Informal talks and document gathering, with HIV/AIDS Focal Point office and UCMB staff

- Interviews with 3 officials
- Participated in bi-annual DFP meeting

Visited projects and organisations in different dioceses (see appendix 3 for the profiling form)

- Kampala: Nsambya Home Care, Reach Out Mbuya, KCCC
- Fort Portal: Virika hospital AIDS clinic, Kyakataru health centre II
- Arua: Ediofe health centre III, Ocodri health centre III, Lodonga health centre III, Maracha hospital AIDS clinic

Preliminary studies in KCCC: April & June 2008

- Qualitative interviews with programme coordinators (9)
- Qualitative interviews with young peer educators (2)
- Participant observations of: Life Skills workshops (HIV/AIDS prevention measure), counselling and home visiting.
- 2 focus group discussions with various staff, discussing the role of Christianity in their work
- Visits to outreach clinics in Lungujja and Mengo-Kissenyi

Preliminary studies in Arua diocese: May 2008

- Qualitative interviews with the DFP and the coordinator of the home-based care programme in Ediofe Health Centre
- Participant observations of: HIV/AIDS sensitisations in 5 different parishes, HIV testing & counselling in 4 different clinics (see above), home visiting with Maracha hosp., and 1 post-test club meeting
- Visit to Arua Hospital AIDS programme (government hospital)

Overview of research activities completed Dec 2008-May 2009

Studies in KCCC: December 2008 – mid-February 2009

- Participant observations of counselling, home visits and clinical practice
- Participant observations of daily morning prayers, general and departmental meetings etc.
- Preliminary feedback discussions with respectively home visiting and counselling department
- Qualitative interviews with counsellors (8)
- Qualitative interviews with community health workers (9) and 1 coordinator
- Qualitative interviews with 5 clients
- Simple profiling questionnaire filled by community health workers (21)
- Visit to outreach clinic in Bukoto

28 May 2009: Feedback meeting with entire organisation.

Studies in Arua diocese: mid-February – May 2009

Ediofe Health Centre

- Participant observations of home visiting
- Qualitative interviews with community counsellors (5)

Maracha Hospital AIDS clinic

- Participant observations of pre- and post-test counselling, on-going counselling, home visiting (only 2 days) and clinic consultations
- Qualitative interviews with counsellors (3) and clinic coordinator
- Qualitative interview with hospital managers (3 together)

Pajulu Post-Test Club

- Participant observations of club meetings

Arua Hospital AIDS Programme (government)

- Participant observations of counselling and 1 home visit

18 May 2009: Feedback meeting with representatives from all of the above organisations

Other activities

- Interviews with US organisation officials (2)
- 1 day visit to St. Mary's hospital Lacor in Gulu
- Participated in national HIV counsellors conference 6-8 May 2009
- 25 May 2009: Feedback meeting with various Catholic stakeholders at UCS
- Visit to SCOT, reading in counsellor training manuals
- Visit to IPASC in Aru, DR Congo.

Appendix 3: Profiling questionnaire for organisations**Contact:** _____**Name of organisation:** _____**Type of organisation:** _____**Year initiated:** _____ **By whom:** _____**Catchment area(s):** _____**Target groups:** _____**No. of clients:****No. of employees/volunteers:**

Activities:**HIV/AIDS Prevention:** Information campaigns/sensitizationBroader based: IGAs
Vocational training/education
“Positive” leisure activities**Treatment/care/support for People living with HIV/AIDS**ART
OI
PMTCT
Prophylaxis
Food support
Basic care kits
Pastoral Care/Psychosocial support
Home-Based Care/Community support structures
Social/material support
IGAs
Vocational training/education/job opportunities
Post-test clubs/PHA groups**VCT**Testing facilities
Pre-, post-test and on-going counseling

OVC support Orphanages
 Schooling
 Vocational training & career guidance
 Support of OVC' caretakers

Names of programmes/departments in organisation:

Funding agencies:

Appendix 4: Examples of interview guides

General interview guide for KCCC programme coordinators (2008)

Introductions

My name is Louise Rasmussen I am PhD student from Denmark doing research on HIV/AIDS activities within Catholic organizations in Uganda. After spending some time getting a general overview of AIDS activities in the Catholic sector, I am now focusing on a few specific projects; here in Kampala it is KCCC.

I would like to ask you some questions concerning the background, goals, method & techniques, and the challenges you face in the programme you are heading.

And it is ok if a record this interview; I will not mention your name if I quote something you have said.

Opening question: can you tell me about your background in terms of education and job experience, and how long you have been working here?

Rationales

- Can you tell me when and why this programme was started?
- What is the overall goal with the programme?
- What are the problems this programme tries to address?

Methods & techniques

- What approach or which methods do you use in the programme?
- What are the advantages and disadvantages with this approach?
- If the approach or method has been changed over the years, ask why.

Successes and challenges

- What kind of impact have you noticed?
- What have you learned when running this programme?
- What challenges does the programme face?
 - What can be done to meet these challenges?

Interview guide - AIDS coordinator Ediofe Health Centre (2008)**Introductions**

- Can you tell me your background; education, previous jobs.
- How long have you worked here?

Rationales

- Can you tell me, who came up with the idea of doing home visits with community counselors, and what the rationale behind it was?
- What is the overall goal with this kind of HBC?
- Who came up with the idea of having a post-test club; what was the rationale behind it?

Specific practical questions

- How do you identify the patients to be included in your home-based care programme? And then how do you make contact with them?
- Are all those who receive ART or other drugs/services from AHAP, which are in your catchment area, in the programme?
- What is your catchment area?
- How were the community workers recruited?
- The HBC was started in 2004, right? Was the VCT also started then or earlier?

Successes and challenges

- What kind of impact do you think your HIV/AIDS services and activities have had?
- In the time you have been coordinating this programme, what have you learned?
- What challenges does the programme face?

Interview guide – KCCC counsellors (2009)**Introductions**

- PhD student from Denmark, a social scientist specialised in HIV/AIDS, civil society organisations and development. I'm doing this research on treatment, care and support to PHAs in Catholic organisations independently for my PhD, I have not been contracted by any organisations to this research.
- In this interview I am interested in your views on the work you do as a counsellor and the challenges you face, and your experiences.
- For anything we discuss in this interview, your identity will be kept anonymous. If I use something you said I will not use your real name
- Do you have any questions about my research?
- Is this interview ok with you? Is recording ok?

- **Introduction of counsellor:** How long have you been working with KCCC? When did you start working as a counsellor? If worked as a counsellor elsewhere, what difference have you seen in KCCC? What is your educational background? Have you worked in another profession before becoming a counsellor?

Rationales and techniques of counselling

- Even though I have seen a bit of what happens in the counselling here, can you tell me in your words, what goes on in a counselling session? What do you try to do?
- In your point of view, what is the overall goal with the counselling you give in connection with HIV testing?
- What is the overall goal with other on-going counselling of clients? Why is this counselling needed?
- What are the problems or challenges that counselling are to address?

Counselling experiences and views

- In your experience what are the most challenging situations to handle as a counsellor?
- What situations or experiences have made/make you happy/pleased?
- What are the most important issues to address to ensure Positive Living? (In your point of view, why must Positive Living be ensured?)
- In your point of view, how should discordant couples/women who wants to produce/client who refuse to disclose to their spouse be handled?

Challenges and lessons

- Generally as you do your work as a counsellor, what frustrates you?
What challenges do face as a department?
- How do you think these challenges could be addressed?
- Since being a counsellor in KCCC, what have you learnt?

Interview guide – KCCC clients (2009)**Introductions**

- PhD student from Denmark. Social scientist specialised in HIV/AIDS, civil society organisations and development. Doing study for my PhD studies to see how people living with HIV/AIDS are helped in this organisation, in order to discuss and to see how help to people in this situation can be improved generally
- This is Norah who translates for me.
- This it is not an exam, not an interrogation, it about sharing ideas, and mostly I am interested in hearing your ideas, your views and your experiences.
- I will ensure your confidentiality and anonymity, this means that I will not disclose any personal information about you I come to learn during this interview to anyone, not even to anyone working at KCCC. If I decide to your story as a case study in my report I will make up a name and perhaps change some details so that people cannot recognise you.
- Do you have any questions about my research? Is the interview ok? Is recording ok?

Opening questions

- Can you tell me how you first decided to go to KCCC/what made you go to KCCC for testing or treatment?
- If client has not tested positive at KCCC, where did you first test? What happened that made you go for testing? Why did you later come to KCCC?
- When did you start on treatment?
- How have you been doing since starting on treatment?
- What problems or challenges do you face?

Facts to be covered during the interview

- Spouse/partner? Status. Disclosed to? Died, when?
- Number of children. In school?
- Level of education
- Occupation
- CD4 count when first testing. CD4 count when starting on treatment, and now.

Exploring questions

- When you learnt you were HIV positive were you shocked? Or did you expect it somehow?
- When you learnt you were HIV positive did you tell anyone at first? Who? Or did some time pass before you felt you could tell anyone? What made you disclose then?
- Did you tell anyone that you started on treatment?
- What do you think of the services provided by KCCC?
- If have been client in other institution, do you think KCCC is different and what is the difference?
- What recommendation will you give to KCCC?

Interview guide – Maracha Hospital counselors (2009)**Introductions**

- Research: Social aspects of living with HIV/AIDS and social aspects of providing treatment and care. Focus on catholic service providers/ Independent research for academic purposes.
- Not an exam/interrogation, want to hear your views to learn from you.
- Anonymity and confidentiality. Any questions? Recording ok?

Details on counsellor

- How long have you been a counsellor here?
- Where did you take your certificate?
- What is your education level?
- Why did you want to become a counsellor?
- Have you worked in another or similar profession before?

Rationale and techniques

- What usually goes on a – pre-test / post-test sessions?
- According to you, what is the importance of counselling in connection with HIV testing?
- What messages do you emphasise in your counselling? What do you normally discuss in counseling sessions?
- I see more women than men coming for testing and for treatment. Why do you think that is the case?

Challenges and lessons

- What challenges do you face as a counsellor?
- Since being a counsellor, what have you learnt?

Interview guide - Ediofe community counsellors.**Introductions**

- Research: Social aspects of living with HIV/AIDS and social aspects of providing treatment and care. Focus on catholic service providers/ Independent research for academic purposes.
- Not an exam/interrogation, want to hear your views to learn from you.
- Anonymity and confidentiality. Any questions? Recording ok?

Details on counsellor

- Where do you live?
- Age, level of education and profession, marital status, number of children.
- In which areas do you visit clients? How many?
- How did you come to know about this work?
- How were you recruited and what attracted you?

Rationale and techniques

- According to you, what do you consider as your role as a community counsellor?
- Whenever you visit a client, what do you normally do/discuss?
- Why is it needed/what is the benefit of having community based counsellors?
- Why is home visiting needed/how is it beneficial?
- How can you make sure clients adhere to their treatments?
- How do you handle visiting clients who have not disclosed?

Challenges and lessons

- As a community counsellor, what challenges do you face? What are the most challenging situations you have/have had to handle as a community counsellor?.
- What situations bring you joy?
- Since being a community counsellor, what have you learnt?

Living with HIV

- When did you learn you were HIV+?
- What made you go for testing?
- Were you shocked when you learnt about your status?
- Did you tell anyone at first? Whom have you disclosed to?
- Are you on ART yet? If yes, have you told anyone? How have you been doing on ART?

Appendix 5: Example of focus group discussion manuscript

Manuscript

Introduction of me and the project (5 min)

My name is Louise Rasmussen, and I'm from Denmark. I am a social scientist, doing a PhD on Catholic responses to the AIDS epidemic in Uganda. As you know I have been with KCCC for a while, and I have also been to Arua and briefly in Fort Portal. The purpose of my project is to examine different ways Catholic organizations and health institutions respond to the AIDS epidemic in Uganda, both in relation to the prevention of HIV/AIDS and in relation to care, treatment and support for people living with HIV/AIDS.

Information about the interview (2 min)

- The discussion is going to last about 2 hours
- The discussion will be recorded on a digital recorder. The recording and its transcript will not be published to others, but I may use excerpts from the transcript in my dissertation. When I do that, your names will not be mentioned, I will instead use pseudonyms to refer to the different people in the discussion.
- Because of the recording I will ask you to try not to speak at the same time too much
- The discussion is going to take place in English. However, if you at some point feel like you can express something better in Luganda, you can say it in Luganda and my assistant can translate.

Discussion rules (8 min)

- A focus group discussion is a bit different from an ordinary interview. Instead of an interviewer asking questions, the purpose with a focus group discussion is to get the participants to discuss with each other. Therefore, I am asking you to discuss with each other, instead of making answers to me.
- It works like this; I will initiate the discussion with a question or an exercise, and thereafter you are to discuss and debate about the issues, until the topic has been exhausted or I tell you to stop.
- The idea is thus that as a group you will run this discussion almost on your own. But if the discussion gets stuck or if someone is dominating the discussion too much I will step in.
- It is very important for me to stress that in such a discussion there are no right or wrong answers. I am here to hear about your views, experiences, and reflections etc. Also, you should not be too

concerned when you are discussing whether what you are saying will be useful to my project, I'm generally interested in your views and experiences very broadly, and if the conversation goes too much in an irrelevant direction, I will let you know.

- Perhaps you will not agree about everything that you discuss and that will be quite ok with me. The purpose with the focus group is for you to discuss until you have a clear picture of what you agree and disagree on.

Participants introduce themselves (10 min)

Before we really begin the discussion, I will like to ask you to make a brief introduction of yourselves. I am interested in things like your name, your job position or position as a volunteer, and how long you have been working or volunteering in KCCC.

Topic 1 – Christian values & beliefs' role for HIV/AIDS prevention in general (25 min)

The first thing I would like you to discuss is how you think Christian values and beliefs in general are beneficial to the prevention of HIV/AIDS. Please take these pieces of paper and write down at least 3 points about how you think Christian values and beliefs can be or are beneficial to HIV/AIDS prevention. You have 5 minutes.

Participants present what they have written

Do you have any comments, elaborations or disagreements? What did you think when you heard the other's presentations?

Follow-up question: Do you think there are any ways that (certain) Christian values & beliefs can be negative towards the prevention of HIV/AIDS?

Topic 2 – The role of Christian values & beliefs in Uganda's efforts to prevent HIV/AIDS (15 min)

The next thing I will like you to discuss is what role you think Christian values and beliefs have played towards the prevention of HIV/AIDS in Uganda.

- Historically
- Currently

Topic 3 – The role of Christian values & beliefs in KCCC's prevention efforts (25 min)

Now, we are going to discuss more specifically about the work you do here in KCCC.

I would like you to take 5 minutes and think individually about a situation or experience where you think that the use of Christian values & beliefs really made a difference towards an HIV/AIDS prevention effort.

Who would like to share their thoughts?

Reactions? Do you have any comments, elaborations or disagreements?

Topic 4 – The role of PHAs in HIV/AIDS prevention (15 min)

Next, I would like you to discuss: what role do you think people living with HIV/AIDS can play in HIV/AIDS prevention?

- And what role do PHAs play in KCCC's prevention efforts?

Topic 5 – The causes of HIV/AIDS (25 min)

The final discussion topic deals with the causes to the spread of HIV/AIDS.

First, I would like you make a list of what you, personally, think are the 5 leading causes to HIV/AIDS in Uganda. Afterwards, I would like you to share your lists with the others. You have 5 minutes to make your individual list.

End - Brief evaluation

How did you find the discussion? How did I find the discussion?

Appendix 6: Questionnaire for profiling the KCCC community health workers

Name: _____

Female/male _____

Age: _____ Educational level: _____

Employed as CHW since: _____ Previous job: _____

Place of residence: _____

Married widowed separated/divorced single

Number of children: _____ Number of dependants: _____

How many children in school and what level? _____

Religious affiliation: _____

Clients in which areas: _____

How many clients: _____

Other responsibilities in KCCC? _____

Also a client? _____ On treatment? Since when: _____

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English summary

This dissertation studies three Catholic organisations in Uganda involved in providing ‘treatment, care and support’ to people living with HIV/AIDS. Based on ten months’ fieldwork in different types of Catholic AIDS projects in Kampala and Arua dioceses, the dissertation provides a comparative perspective on divergent ways that bio-medical treatment, spiritual care and social support to people living with HIV/AIDS are combined and negotiated in the context of the antiretroviral (ARV) treatment ‘scale-up’ that has taken place in many African countries since 2004.

Combining Foucault-inspired perspectives with ethnographic studies, the dissertation explores the intersections between the Catholic organisations’ religious ideals and practices, ‘global AIDS treatment’ and the self-government the organisations attempt to promote among people living with HIV/AIDS. The analysis focuses in particular on practices of counselling and home visiting as key sites of negotiation and debate about how to govern the conduct of people with HIV/AIDS.

The dissertation makes its main argument in two parts. First, I argue that the dominant forms of government in the three Catholic organisations centres around disciplining and educating people living with HIV/AIDS to follow ‘the rules’ of ARV treatment. This form of government includes working on the responsibility of people with HIV/AIDS and their families to independently address any social or economic barriers to following these rules. With this dominant form of government, the Catholic framing of ‘holistic HIV/AIDS care’ as a matter of combining medical healing with spiritual and material assistance is side tracked, and pastoral care approaches are reconfigured as psychological techniques of self-transformation.

I then analyse how people living with HIV/AIDS negotiate following ‘the rules’ with trying to realise the potentials of ARV treatment in their own lives. I argue that the effects of the Catholic organisations’ practices of ‘treatment, care and support’ include producing new life-prolonging potentials, but also new uncertainties and inequalities.

By studying Catholic organisations involved in the ARV treatment ‘scale-up’, this dissertation contributes with a unique perspective on the scale-up. The dissertation highlights how the massive allocation of resources for ARV treatment in Sub-Saharan Africa provides only a partial potential to

prolong life, and how treatment providers at the same time produce new social inequalities, by committing ARV patients to follow a meticulous self-government regime. For Catholic organisations involved in the ARV treatment scale-up, we can trace how promoting individual responsible self-government is replacing ethical questions of how to ensure human dignity in times of adversity with spiritual and material assistance.

Danish summary

Denne ph.d. afhandling omhandler tre katolske organisationer i Uganda, der er involveret i behandlings- og støtte projekter til folk der lever med HIV/AIDS. Afhandlingen er baseret på ti måneders feltarbejde i forskellige typer katolske AIDS projekter i henholdsvis Kampala og Arua stift. Afhandlingen tilvejebringer en komparativ analyse af forskellige måder hvorpå biomedicinsk behandling, sjæle omsorg og social støtte til AIDS patienter kombineres og forhandles i forskellige katolske projekter i forbindelse med udbredelsen af anti-retroviral (ARV) medicin i Uganda.

Ved at kombinere et Foucault-inspireret teoretisk perspektiv med etnografiske studier, undersøger afhandlingen forbindelseslinjerne mellem de katolske organisationers' religiøse idealer og praksisser, det globale styringskompleks omkring AIDS medicin og de selvstyrings-praksisser organisationerne forsøger at fremme blandt AIDS patienter. Analysen fokuserer hovedsageligt på AIDS rådgivning og hjemmebesøg som centrale arenaer for forhandlinger og diskussioner omkring hvordan AIDS patienters' selv-styring skal styres.

Afhandlingen argumenterer i den første del, at den dominerende form for styring i de tre organisationer går ud på at disciplinere og uddanne AIDS patienterne til at følge 'reglerne' for ARV medicin og 'Positive Living'. Denne form for styring involverer også en ansvarliggørelse af AIDS patienterne til selvstændigt at adressere sociale og økonomiske barrierer for at følge 'reglerne'. I den forbindelse bliver katolske idealer om en helhedsorienteret indsats, der forbinder medicinsk, spirituel og materiel 'helbredelse' kørt ud på et sidespor, og sjælesorgs-praksisser bliver omdefineret som psykologiske selv-forandrings-teknikker.

Afhandlingen analyserer dernæst hvordan AIDS patienter forsøger at udfolde ARV medicinens potentiale i deres hverdagsliv. Disse analyser illustrerer, hvordan de katolske organisationer, gennem de ovennævnte styringspraksisser, er med til at producere nye livsforlængende potentialer, mens også nye usikkerheder og uligheder.

Ved at studere katolske organisationer, der er involveret i udbredelsen af ARV medicin, bidrager afhandlingen med et unikt perspektiv på dilemmaerne og udfordringerne ved ARV medicin i Afrika. Afhandlingen sætter fokus på hvordan de enorme donor midler, der er tilsigtet ARV medicinens udbredelse i Afrika kun delvist bidrager til at skabe livsforlængende potentialer, og hvordan ARV programmer samtidig er med

til at skabe nye sociale uligheder ved at kræve at AIDS patienter følger en omstændig form for selv-styring. I den forbindelse, kan vi for katolske AIDS projekter aflæse, hvordan spørgsmål om individuel selv-forvaltning afløser etiske problemstillinger om hvordan menneskelig værdighed sikres igennem spirituel og materiel støtte.