# LIVING WITH HIV/AIDS: AN ETHNOGRAPY OF CARE IN WESTERN KENYA

A thesis submitted to The University of Manchester for the degree of PhD in the Faculty of Humanities.

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Social Sciences/Social Anthropology

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## Abstract

This thesis, 'Living with HIV/AIDS: An ethnography of care in Western Kenya', is based upon 18 months of ethnographic fieldwork carried out in Central Nyanza, Kenya, between 2005-2007. It studies practices of care against the backdrop of the HIV/AIDS epidemic, which has impacted the region severely. The thesis explores how home and hospital are established as domains of care through practice. It draws upon ethnographic material collected from within a District Hospital, a Community-Based Organisation and people's homes.

The thesis follows practices of care across divergent domains of social life to consider how practices of care within Luo networks of kinship and relatedness intersect with governmental interventions to manage HIV/AIDS. The thesis describes two governmental projects introduced to administer HIV/AIDS care in this region. It considers Home-Based Care, an HIV/AIDS response in which Community Health Workers are trained to support particular aspects of care at home, focusing on the practices of care employed by Community Health Workers as they visit sick people at home and attend organisational meetings. The thesis also describes the landscape of HIV care in the District Hospital, including the delivery of anti-retroviral therapy. The focus here is on the relationships between caring practices in the hospital and at home, and the divergent responsibilities to care experienced by hospital staff and family members.

The main argument of the thesis is that care is a particularly useful analytical tool for anthropology because practices of care take place across many different domains of social life, cutting across the boundaries that have formed the traditional focus of anthropological study. Studying practices of care illuminates the production of bounded domains of social life whilst simultaneously drawing attention to similarities of practice across different domains. Care provides a way of understanding the complex social landscape that has developed as people in Western Kenya endeavour to live with HIV/AIDS.

Submitted by Hannah Brown to the University of Manchester for the degree of PhD in Social Anthropology, in the faculty of Humanities, 2010.

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I declare that no portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning

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## Acknowledgements

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## Map of Kenya

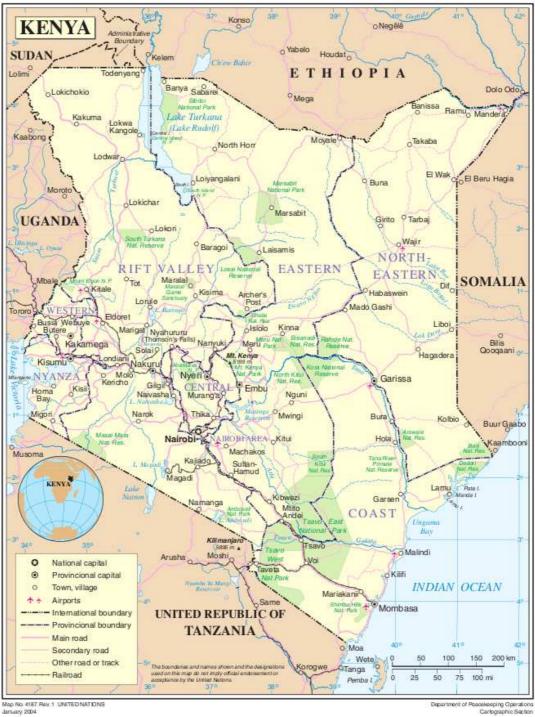


Figure 1. Map of Kenya

# Map of Nyanza Province



Figure 2. Map of Nyanza Province

## Introduction(s)

Mtu ni watu (A person is people – Swahili proverb)

*"Bi mos wendo"* (Come and greet our guest<sup>1</sup>). Hearing this instruction, imparted to the shy children of the many Luo homes I visited during fieldwork in Western Kenya, I responded by copying Luo adults in their dealings with children, with an encouraging, *"Bi mosa"* (Come and greet me). Greeting is the way to begin things in the part of Western Kenya which is described in this thesis, and greetings can extend for some time as people share news of family members and friends in common, before they get to the point of their meeting (if indeed there is any beyond the greeting itself). Greeting is also a fitting way to begin this thesis, because it is through greetings, introductions and naming that one first learns of the ways that Luo people mark out their relationships to others, relationships often characterised by obligations to give and receive care. In greeting, *mtu ni watu* – a person is people, because greetings and introductions enable Luo people to situate themselves and others in terms of relationships to other people, and to the places through which such relationships are engendered. Through everyday greeting one is also thrust into networks of concern around health and well being; *"A*re you well? Are people from your home well?<sup>2</sup>", runs one common greeting pattern.

"Luo people can find relationships (*Wede;* sing. *Wat*) everywhere," my first Luo teacher told me from within the confines of a dreary Manchester University office, long before I began fieldwork in the market town I refer to as Kagot<sup>3</sup>, in Central Nyanza. She was right; the ability of so many Luo people to trace their relatedness to the current American president is a contemporary confirmation of this (Carotenuto and Luongo 2009: 14, Madiega et al. 2008: 7). The importance for Luo people of emphasising relationships to others over the (dangerously isolated) independent individual is demonstrated both by the searches for networks and connections that mark meetings with new acquaintances and by the way Luo people address others. A polite interlocutor knows that the preferential form of address is often neither a person's baptismal or Anglicised name, nor a Luo name

<sup>&</sup>lt;sup>1</sup> Unless otherwise stated, foreign language quotes are in Luo, also called Dholuo. The abbreviation Swa. for Swahili, will prefix quotes in Swahili.

<sup>&</sup>lt;sup>2</sup> Ingima? Joodi gingima? As an adjective, ngima means healthy, fit, well, complete, in total. The noun ngima means health, life, being alive (Bole Odaga 2005: 229)

<sup>&</sup>lt;sup>3</sup> I use real names for cities and regions, and the names of public figures such as politicians. All other place and personal names in this thesis are pseudonyms.

which says something about the circumstances of a person's birth<sup>4</sup>, used on formal documents and among certain peers. Ideally one uses forms of address (particularly to those older than oneself) which emphasise relationships to others and social status. Indeed, it is often considered rude to address someone by name, as simultaneously "too distancing (individuating and thus negating the web of relations that link one to the other) and too personal (touching upon a vulnerable core of personhood)" (Geissler and Prince 2004: 107). Preferred forms of address include, where appropriate, titles such as teacher, doctor, priest and big man/polygamist<sup>5</sup>; teknonyms; Mother of Paul, father of Otieno<sup>6</sup> and what one might call demonyms; names which flag a relationship to a particular place and clan; woman from Ugenya, son or man of Sakwa<sup>7</sup>.

Luo naming practices are more than mere recognition that the authority and position of an individual is a product of relationships to places and to other people; they celebrate this connectedness and the networks which link people, places and the achievements of reproduction and hard work. In an echo of Goffman's (1956: 486) suggestion that the practices of deference and demeanour contained within greetings are ritual practices which demonstrate the ceremonial nature of selfhood and "provide a continuous symbolic tracing of the extent to which the recipient's ego has not been bounded and barricaded in regard to others", Cohen and Atieno Odhiambo argue that when Luo people greet one another, the individual may initiate the greeting, but in reality that salutation is "society greeting itself" (1989: 27). They continue; "It is the stranger who has to answer to the question: *In ng'a*? ('Who are you?') You do not in an important sense exist until you reveal your networks and, more importantly, until this network can be verified by your interrogators" (Ibid.).

#### Practices of care

This thesis is concerned in part with how such networks of relationships shape and are shaped by the obligation to provide care to others, particularly those who are very sick. However, I situate my interest in such networks not solely within studies of Luo kinship and relatedness, but by thinking about such networks of care more broadly within the context of shifting projects of government (cf. Foucault 2002 [1978]). In particular, I describe how obligations of relatedness intersect with the regimes of health care organisation and administration that have developed in this part of Kenya as a

<sup>&</sup>lt;sup>4</sup> E.g. Otieno, meaning a boy born during the night time (SeeBlount 1993, Ocholla-Ayayo 1976: 182-4).

<sup>&</sup>lt;sup>5</sup> japounj, daktari, japolo, jaduong'

<sup>&</sup>lt;sup>6</sup> MinPaul, WuonOtieno

<sup>&</sup>lt;sup>7</sup> NyaUgenya, WuodSakwa, JaSakwa

direct response to the impact of the HIV/AIDS epidemic, which influence how and where people provide care to others.

I discuss two key governmental interventions in this thesis. Firstly, I examine 'Home-Based Care'; an initiative which involves supporting people living with HIV/AIDS and their caregivers at home. Secondly, I consider attempts within government health facilities to care for people who are HIV+ and dying of AIDS, including care facilitated through the introduction of anti-retroviral therapies (hereafter ARVs). I draw upon ethnographic material collected during fieldwork within a District Hospital; a Community-Based Organisation carrying out Home-Based Care; and numerous people's homes.

Broadly speaking, this thesis focuses on the spatial practices of care in circulation around home and hospital as domains of care. I describe how caring is spatialised both in the sense that it is located in particular places, but also in the broader sense that caring practices are heavily implicated in the enactment (cf. Mol 2002) of domains of care. Caring practices in Kagot emphasise obligation, hierarchy and responsibility; that is to say they *organise* domains of care. Caring practices also underline the meanings and associations which cohere around domains of care. My argument is that it is only by following the practices of care which produce, link and cut across the boundaries around these domains of care that we can make sense of the complex topography of care which exists in this part of Western Kenya, and the place that recent responses to HIV have within it.

Influenced by critiques of anthropology's use of theoretical paradigms and academic practices which have conflated locality and culture, particularly though the practice of fieldwork (Gupta and Ferguson 1992, 1997a, Olwig and Hastrup 1997), in Kagot I developed a field site defined not so much by a location but rather by practices. I used the relationships that I made with my informants to follow relationships and practices of care, beginning in Kagot District Hospital, where I had contacts that allowed me to begin fieldwork. I later moved to a Community Based Organisation (which I call Kagot Development Group) and into people's homes, sometimes coming back into the hospital and the organisational office as people I came to know sought care there.

The practices of care which I followed and the people whom I worked with in Kagot and Ramira were mobile and it was their practices and movements which defined my field site(s). Yet they were not endlessly mobile, but moved between places. Gupta and Ferguson (1997b: 35) write; "Ethnography's great strength has always been its explicit and well-developed sense of location, of being here–and-

not-elsewhere." However, they continue; "this sense of location has too often been elided with locality, and a shift of location has been reduced to the idea of going "elsewhere" to look at "another society". In this thesis I side-step some of these critiques, not by "siting culture" (Olwig and Hastrup 1997) but rather by siting practice. The social practices of care which I followed moved between relatively bounded locations; home(s), hospital, and the office of Kagot Development Group. Crucially however, rather than becoming a framework or site providing a backdrop for thinking about care, this topography of practice became for me my central research question. How are home, hospital and organisational offices established as domains of care through caring practices and how do these divergent domains of care relate to one another?

In thinking about care as social practices, this thesis sits within an intellectual tradition often broadly referred to as 'Practice Theory'. Practice Theory has a long, complex and divergent history. In this thesis, I do not attempt to revisit this vast and diverse collection of material nor to evaluate the usefulness of 'practice theory' broadly speaking, as an analytic tool. It is not that I regard such a project as an unworthy one. However, such an endeavour is outside the scope of this piece of work, and these issues have already been considered in depth elsewhere (e.g. Gherardi 2006: 20-41, Ortner 1984, Schatzki et al. 2001).

However, it is worth mentioning the specific sense of the term practice (which some might consider a branch of 'practice theory') which I draw on in this thesis, which largely comes from recent work in Science and Technology Studies and Organization Studies. This literature, has for example, suggested that the practices of laboratory technicians and scientists (Latour and Woolgar 1986), like those of many social scientists (Law 2004) *produce* rather than describe the 'real world out there'.

John Law (1994) has argued that studying practices ethnographically is not a means by which to uncover hidden orders which inform practices but rather sheds light upon modes of ordering; a sociology of "verbs rather than nouns", as he puts it. The key insight here, I think, is that practices are not 'just' what people do, but also how people know, organise knowledge about and "enact" (Mol 2002) the world around them; "Cultural practices *are* action" (Swidler 2001: 76).

## Theorising care

In theorisations of care within and outside of health care, there has been a tendency to oppose care to a domain of objective rationality so that care remains exclusively in the province of the emotional/female/familial, and to divide care up and distinguish between types of care which are either technical or emotional. In these divisions and oppositions the external division (care – rationality) and internal division (technical – emotional) are the same conceptual division in that they draw upon similar understandings of the relationship between emotion and care.

Within this ontology, nursing is understood to epitomise care, and care nursing (Leininger 1980, 1984), with all its feminine associations, except when nurses are unnecessarily drawn away from care to manage technical issues or paperwork (e.g. Penn-Kekana et al. 2004). Care is also often understood to be tightly bound up with the emotional closeness and love associated with the familial realm and often with particular kinds of relationship such as the one between mother and child (Noddings 1984: 128-131, Ruddick 1989). This is a view-point within which technology and care are understood as incompatible and doctoring is curative rather than caring (cf. Mol 2008, Pols 2009, 2010). It is an ontology which looks something like this:

Care (external division) or Emotional Care	Cure (external division) or Technical Care	
(internal division)	(Internal division)	
Nurse	Doctor	
External to the body	Internal to the body	
Female	Male	
Familial	Institutional	
Emotional	Rational	
Subjective	Objective	

This is of course, a crude simplification of theorisations of care and there are some important exceptions. Tronto (1993) has interrogated the production of such divisions and questioned how it is that women have become associated with care and a related realm of emotion and nurture. Others

have sought to understand multiple meanings of dependency via its shifting meanings (Fraser and Gordon 1994) and its practices (Kittay 1999). Mol (2008) and Pols (2009, 2010) have used ethnography to break down the dichotomy between care and technology, in Mol's case by broadening the concept of doctoring to a much wider group of people involved in care than just doctors (Ibid.: 62-5). Elsewhere, anthropologists of nursing in the UK have argued that the idea of emotional 'closeness' as an aspect of 'care' is not intrinsic to British nursing, but has developed as part of recent shifts in nursing philosophy (Armstrong 1983, Savage 1995). Others have worked with hospital support staff to emphasise that nurses do not have the monopoly over therapeutic care in hospitals (Hart 1991).

This latter work is influential in how I have come to think about care, not least because it has encouraged me to question the assumptions of closeness, emotionality and intimacy often understood as central to care. However, while my argument derives much from this important work, here I want to use these insights to make a slightly different argument for care. For example, both Tronto and Mol theorise care by developing other kinds of theoretical boundaries, whether between an ethic of care and a justice morality, as in the case of Tronto and other feminist philosophers (e.g. Gilligan 1993 [1982], Kittay 1999), or between a logic of care and one of choice, as in Mol's case. My argument here is that it might also be profitable to stop trying to pin care down by thinking about boundaries around care or within care and instead to recognise that what is so useful about care is precisely its slippery and enigmatic character. Here, I position myself against those who have argued that because care is so very difficult to define we should do away with it as a theoretical concept. I disagree with the critical review of feminist theorisations of care which prompts Thomas (1993) to the conclusion that; "there is no such thing as 'care' in theoretical terms. It is a descriptive concept like 'housework' or 'manufacturing work' which for sociological purposes has to be placed in theoretical context" (Ibid.: 666).

My argument is that one way of attending to "mess" (Law 2004) in social life is to recognise the benefits of slightly 'messy' theoretical tools, which draw upon an understanding of theory which is closer to its etymological roots in the Greek term *theoria*, meaning contemplation, than an understanding of theory as a frame or model with which one can explain social life (cf. Latour 2005). If theory is understood as contemplation it amounts to a much more active, tentative and open undertaking than if theory is thought of as a "series of ideas and general principles which seek to explain some aspect of the world" (Chambers English Dictionary 2009). Via this contemplative

theoretical mode, what I have ended up with is a purposefully minimal definition of care, which, because it is not grounded in particular real-life descriptions, does not draw upon assumptions about what care is or who does it, and is not based within or modelled on particular social relationships, like the mother-child bond, or the conjugal partnership. So it does not assume that care happens only between particular kinds of people, or indeed only between people, or only in particular places.

My definition draws heavily upon Mayeroff's (1971) essay *On Caring* in which he is also wary not to assume where and how caring might happen. From this rather wonderful philosophical essay I draw two key points. Firstly, caring is other directed in its concern for the growth or development of the other. Although one can also care for oneself, Mayeroff suggests that caring for oneself and caring for the other are similar and comparable activities (Ibid.: 59-60). Secondly, Mayeroff suggests that through caring, we are "in-place" in the world. We are in-place, he argues, because practices of care mark out our relationships with others. This 'being in-place' is not a fixed position, but a dynamic state which must be continually reaffirmed and renewed as we respond to the needs of others and ourselves (Ibid.: 68-72). So practices of care are other-directed through their concern for the other, and relationally locating. This is, I argue, a definition which is suitably vague, complex, slippery and messy to be a useful theoretical tool. It resists dichotomising polarities and instead questions how meanings of care are negotiated through practice. As a definition which centres on care as practice, it is an active definition, almost an appeal for ethnography. This is precisely the appeal which this thesis attempts to answer.

Beginning from this focus on care as practice, my argument is that care becomes useful as an analytic tool for anthropology because caring practices are central to all aspects of human life and because practices of care cut across boundaries as familial/medical/institutional and emotional/rational. Through its capacity for crossing boundaries, care provides a way both of illuminating such boundaries and drawing attention to similarities of practice across such boundaries. My argument is not that such boundaries form a map which defines where or how social practice happens. Instead I argue that these boundaries are *produced* through social practices, and that ethnographic analysis can reveal how such boundaries are made (powerful), maintained and traversed (cf. Luedke and West 2006). Practices of care thus cut across the institutions which have so often formed the frameworks for anthropological engagement, institutions which have been both abstract; 'kinship', 'domestic', 'gift/exchange' and material; 'hospitals', 'clinics'.

### Care as methodology

Doing fieldwork, care increasingly became for me a methodology as much as an object for study; a motif for a way of being in the field. Schooled in an anthropology which had become highly critical of the notion of a neutral, detached observer (e.g. Bell et al. 1993, Okely and Callaway 1992) and the problems inherent in the notion that anthropology's task was to *represent* 'the other' (Clifford and Marcus 1986), I never doubted that "our understanding of others can *only* proceed from within our own experience, and this experience involves our personalities and histories as much as our field research" (Jackson 1989: 17, emphasis in original). What came as more of a surprise was the way in which theory, methodology and the experience of doing fieldwork became entwined together.

In Kagot, reflecting upon my own research, I became concerned with carrying out *careful* ethnography, in a sense which I took from the Swahili term, *polepole*. *Polepole* is usually translated as 'slowly', but while it does mean slow, the term also carries the connotations of gentle, unhurried, observant, open, unflustered, *care*ful. To describe a person as slow, *polepole*, is not an intellectual dig but a friendly compliment. *Polepole* underlines the humility required to get things done in Kenya; by sitting quietly in offices, patiently letting the hours pass as a sign of respect to the authorities whose permission one needs to remain in the country or to carry out research, sitting with somebody at their bedside, passing the time, spending long enough visiting someone that they can have the chance to prepare food to share with you.

Being *polepole* is about taking time to greet people, and never being in a rush to get to the next meeting. It is the basis of the compliment I received from a nurse, Sister Carolyn, (which I discuss in Chapter 6) for not leaving a woman in a slow and difficult labour, but just standing quietly waiting, comforting, distracting, and simply remaining in the room with the nurse and her patient. Being careful/slow was also a helpful way of staying with the practice, not assuming too soon what care might be and where I might find it, but patiently observing what people were doing and allowing fieldwork to take its own time, so that my fieldwork plans and practices could work together in a loose developmental cycle.

#### Locations

Most of what is described in this thesis took place in Kagot town, a district centre and market town a few kilometres from the shores of Lake Victoria and approximately 50km from the regional capital of Western Kenya, Kisumu. I also carried out fieldwork in a neighbouring village which I call Ramira,

some 4km from Kagot town. Most of those who live in the town, and the overwhelming majority of those who live in the rural areas of Kagot district, describe themselves as Luo people, or *JoLuo* (sing. *JaLuo*) in the Luo language, *Dholuo*.

Kagot is a bustling, lively town; on market days the town throngs with people buying and selling fish, household goods, second hand clothes, Ugandan fabric for dressmaking and every other necessity. The whole town is busy as people from across the district use the opportunity of their market-day visit to carry out other business in town; at one of the many pharmacies, the post office; the courts; the district offices; the police station or the hospital. Those who are better off take a meal of fish or chicken and *kuon*, a staple food made from ground maize or millet, in one of the many *hotelis* (Swa. hotel, cafe or restaurant) in the town; others fill up on soda; on *chai* with chapatti or doughnuts; on a calabash full of thin porridge known as *nyuka*; or simply stay hungry. Everywhere people stop to talk, greet friends and ask for news of others.

However, one need not look far behind the market-day best of bright outfits and carefully ironed clothes, to begin to see some of the difficulties of everyday life for many of those who live in and around Kagot. People are always ready to comment on the high prices in the market; "Eh! Kagot is too dry, it is ever expensive!" they complain. Few people purchase luxuries like fruit, or meat. High levels of joblessness are made obvious by the great huddle of young men waiting with *bodaboda* (bicycle taxis) at road junctions, to serve the thin trickle of customers who are well off enough to get a lift home, rather than walk.

HIV and TB are serious health problems in the district. Alongside the presence of endemic malaria and the high incidence of fatalities on Kenya's notoriously dangerous roads, the high HIV prevalence accounts in part for the dreadfully short life that the district's residents can expect; an average of around 38 years (Adazu et al. 2005: 1151). As in other African towns where HIV/AIDS, malaria, TB and related infections are endemic, business in pharmacies and sales of herbal medicines known as *yath nyaluo* (lit. "Luo medicine") is booming, as is the sale of coffins. What is more, the three or four large hotels that have sprung up in the town in the last five years do not rely so much upon the custom of those who live locally, as that of the organisations who book them to hold seminars and training courses, profiting from the growing presence in the town of non-governmental organisations (hereafter NGOs) and other organisations.



Figure 3. Coffins for sale on Kagot's main street, outside Pona (Swa. Heal) Chemist

I first stayed in Kagot in the year 2000, some five years before I began ethnographic fieldwork. Working as a volunteer/trainee for a small NGO<sup>8</sup>, I was involved in a project that was co-ordinating Home-Based Care for people living with (or more often dying from) HIV/AIDS, via health centres and teams of Community Health Workers, across Kagot and a neighbouring district. It was a terrible time to be HIV+ in Western Kenya, and the months I spent in Kagot were a truly life-changing experience.

HIV prevalence at the time was estimated at around 35% (Moore and Hogg 2004: 545), and everywhere people were dying. Mostly they died at home, so that relatives avoided both hospital charges and the excessive costs involved in the transportation of dead bodies, although hospital wards were also full of very sick and dying people. The project I worked on supplied basic drugs and supplies for palliative care and the treatment of opportunistic infections. At this time it was more or less impossible to get an HIV test in Kagot district; only a small mission hospital deep in the rural part of the district had the necessary laboratory equipment, and one had to wait a week for the results, which were sometimes inaccurate. As elsewhere in sub-Saharan Africa, anti-retroviral therapy existed only in dreams and prayers.

As we delivered Panadol; Brufen; multi-vitamin syrup; oral rehydration salts and gloves to protect caregivers from infection, many of our clients died knowing that in other, wealthy countries, life-

<sup>&</sup>lt;sup>8</sup> At this time the only NGO with an office in Kagot town. There are now a number of such organisations. I remain grateful to the British organisation VSO (Voluntary Service Overseas), who funded this placement as part of a scheme called the Overseas Training Programme, now Youth for Development.

prolonging drugs were changing the experience of AIDS from a painful death sentence to a chronic condition<sup>9</sup>. This experience sowed the seeds of my future research project, and although I did not know it at the time, forged relationships which I would draw upon in my future fieldwork. I became interested in care, in what people do after and in the face of AIDS. I wrote about Community Health Workers in my undergraduate dissertation and applied for a PhD studentship. Planning my fieldwork, I realised that most of what had been written about HIV/AIDS focused on prevention, sexuality and risk (Brown et al. 1993, Campbell 2003, Herdt 1997, Herdt and Lindenbaum 1992, Setel 1999) or upon the political inequalities of the disease (e.g. Baylies and Bujra 2000b, Farmer 1992, Parker 2001, Treichler 1999). With a few notable exceptions (e.g. Klaits 2002, Wallman 1996), care had hardly been considered<sup>10</sup>.

Arriving in Kisumu, the regional capital, late in 2005, posters advertising an HIV/AIDS support group at a local church announced, "People are not dying anymore!" As I will outline in more detail in the following chapter, the landscape of HIV care had changed dramatically between 2000 and 2005 and ARVs were becoming accessible at a subsidised cost, and eventually for free at some government health facilities. In my naivety I imagined this would be the beginning of the end of the tragedy of death that had been sweeping this part of Kenya. However, I soon learnt the hard way that ARVs were only a partial solution for the HIV/AIDS epidemic in when I visited an old friend, whom I will call Gaudencia.

On my first trip to Kenya I had lived with Gaudencia in her village. Her husband worked for the NGO I was placed with and I was sent to live with her in order to gain a taste of Luo village life. Gaudencia was a wonderful companion; bright, talkative and welcoming. In those few weeks she welcomed me into her home; taught me rudimentary Swahili and a few words of Luo; shared delicious food with me and told me stories about what she called Luo traditions and culture, tickling my nascent anthropological imagination. I learnt then of her HIV+ status; few people had taken HIV tests in those days, but Gaudencia and her husband had been tested at a private clinic in Nairobi. She tested

<sup>&</sup>lt;sup>9</sup> AZT had been available in Europe and North America since the late 1980's, however many people developed resistance to it quite quickly and others suffered severe side-effects. In the early 1990's things had improved slightly as early versions of combined therapy became available. But it was not until protease inhibitors became available towards the end of 1995 and the development of HAART (Highly active anti-retroviral therapy) that these medications really began to make a difference for people living with HIV/AIDS (AVERT nd, Epstein 1996, Pomerantz and Horn 2003). By 2000, although combined therapy treatments were still being improved, the use of ARVs was widespread in the rich world.

<sup>&</sup>lt;sup>10</sup> The focus of HIV/AIDS research has completely changed in more recent years and now includes the publication of a journal devoted to the subject; *AIDS Care*. Many complain that care is now the focus of research work to the detriment of studies on prevention.

positive, him negative. In the intervening years we lost touch, and I wondered if Gaudencia was still alive.

In 2005 I found Gaudencia living in her mother's shop in a small town on the main road between Kisumu and the Ugandan border. Having separated from her husband, she had left his village with their two daughters to live with her mother. I fought back tears as I greeted her; equally grateful to see her alive and horrified at what this cruel disease had done to her body. After we took soda together, I was shown Gaudencia's TB x-ray with its huge white clumps of TB. She was taking treatment for TB at a nearby district hospital. "They want me to gain weight before I begin ARVs," Gaudencia explained. "Those people want money," her mother complained. "There are so many of us, I think they can just take what they want," Gaudencia added. I had money, and carefully squeezed some folded notes into Gaudencia's treatment. "*Nyasaye omedi*" (God will give you more), she thanked me. But it was to no avail, and the next time I saw Gaudencia's mother, a few weeks later, was at Gaudencia's funeral.

The wide-ranging impact of HIV/AIDS in Western Kenya is eloquently summarised in the phrase popular among those working to mitigate the effects of AIDS in the region; "Those who are not infected are affected." This phrase draws attention to the pervasive impact of HIV/AIDS and emphasises people's shifting needs both as recipients and providers of care. The burden of HIV and AIDS in Western Kenya has changed caring obligations and the organisation of care dramatically over the course of the epidemic and has caused the radical reprioritising and reorganising of a struggling health system. HIV/AIDS positions people in Western Kenya within a dynamic network of funding, epidemiological research, political objectives, outputs, targets and hopes of better, healthier futures. Meanwhile, these factors intersect with personal experiences of loss, complex trajectories of health and illness, death, despair and the daily struggles of survival.

Practices of care continue to change with the more recent introduction of Voluntary Counselling and Testing centres across the region, along with increased access to Anti-Retroviral Therapy which as I write continues to be 'rolled out' to reach more HIV positive people. Alongside and in the light of such interventions, people in Western Kenya simultaneously value and re-value practices of care considered to be 'old' or enduring (but which of course are equally dynamic), such as kin-based care. This thesis is an attempt to bring together some of these threads of experience. The title of the thesis; *Living with HIV/AIDS*, is in part an allusion to an international discourse about 'living positively' and to the new kinds "biosociality" (Nguyen 2005, Rabinow 1992) that seem to be evolving from people's experiences of HIV and AIDS and involvement in the global networks which have formed around this disease. However, *Living with HIV/AIDS* is also more broadly a reference to the wider concern of this thesis to document ethnographically the ways in which the people whom I came to know in this part of Kenya have responded to the impact of HIV/AIDS upon their lives and how they engage with the institutions which have developed to manage it.

Although this thesis cannot answer for the injustice and uncertain causalities of the loss of those whom, like Gaudencia, have had their lives cut short by this illness (cf. Boddy 2007 [1998]), it is at one level an attempt to bear "modest witness" (Haraway 1997) to what one might call, to misquote Scheper-Hughes' (1992) work in Brazil, the "tragedies of everyday life" in this part of Kenya.

The first two chapters provide context to the later ethnographic chapters of the thesis. Chapter One follows HIV/AIDS policy chronologically from the mid-1980's when the disease was first discovered in Kenya and situates HIV/AIDS interventions within broader political and economic context. Chapter Two moves the focus away from the level of national policy to consider why it is that levels of HIV are so high among Luo people who live in Nyanza province, before offering a contextual analysis of the three key terms of the thesis; care, home and hospital.

Chapters Three and Four comprise an ethnographic analysis of a policy known as Home-Based Care which has developed in response to the HIV/AIDS crisis, where Community Health Workers are trained to support the care of those who are sick in their own homes. Chapter Five describes practices of care within the Patient Support Centre, responsible for dispensing the newly introduced ARVs. Chapter Six continues the focus on hospital-based care, comparing the relations of care practiced inside the hospital with those of the home and family. Chapter Seven ends the body of the thesis in the same place that the lives of many people suffering from HIV/AIDS have also ended, on the wards of the hospital. In the conclusion I summarise the theoretical contribution to anthropology made by this thesis.

## **Chapter 1. Contextualising the Epidemic**

This chapter and the one which follows contextualise later ethnographic chapters of this thesis. Over the two chapters I describe how, in the context of the high burden of HIV in Kenya, and Nyanza Province in particular, therapeutic care has become associated with specific meanings and particular institutions; notably home and hospital. I document the arrival more recently of specific kinds of HIV intervention, including VCT (Voluntary Counselling and Testing) centres; Patient Support Centres within government health facilities which provide HIV treatment (including anti-retroviral therapy).

I begin in this chapter by following HIV/AIDS policy chronologically from the first cases of suspected AIDS in the mid 1980's through to the introduction of free ARVs in certain health facilities in 2005 and situating HIV/AIDS interventions within wider political and economic context. The broad argument of this chapter is that AIDS interventions in Kenya can be considered as suggestive of what Appadurai has described as the shifting "geographies of govermentality" resulting from the "profound and transformative crisis" affecting the nation-state (2002: 24). For Appadurai, these changes are characterised by a combination of transformations including the growing privatisation of the state through neo-liberal reform; the increased power and influence of multi-lateral organisations; the growing presence of NGOs and new forms of global governance, in particular via organisations like the UN, the rise of global discourses such as on human rights and the growth of activist NGOs and citizens movements as a means of access to government.

My argument here is that although the political history of HIV/AIDS policy in Kenya is suggestive of just such changes in the geographies of the government of health, these changes are significantly informed by longstanding motifs through which people in Kagot understand their relationship to the state and to health care. In particular, there exists a longstanding sense that the region has lost out to other parts of Kenya in terms of health care provision via what is perceived as the inequitable distribution of health resources across Kenya, based upon political allegiance rather than need or entitlement. This relationship to the state is underlined in the phrase commonly heard among Luo people; "We have not yet eaten the fruits of independence".

### The Moi government and the Kenyan state: 1978-1989

In 1984, when the first positive AIDS diagnosis was made in a district hospital in Kenya (Wambuii 2006: 48), Daniel arap Moi, a Tugen Kalenjin<sup>11</sup> from the Rift Valley Province who had served as Vice-President in the latter years of the Kenyatta presidency, was in the seventh year of a Presidency which was to last until 2002. Moi used the Swahili term *nyayo*, meaning footsteps, to underline the ideology of his regime, diffusing opposition at the time of succession by emphasising continuity and stability. The footsteps he claimed to be following were those of Kenyatta, Kenya's first independent President (Barkan and Chege 1989: 434-5, Haugerud 1993: 81-4, Ogot 1995a:192-3).

By 1985, the Moi regime became increasingly brutal as he consolidated his power (e.g. Atieno-Odhiambo 2002). Moi had moved members of his own ethnic group into positions of power in cabinet and the civil service<sup>12</sup> (Bangura n.d.: 38-40, Barkan and Chege 1989: 438-40, Throup 1987), banned the ethnic associations which were the main location of opposition organisation (Barkan 1992: 179) and rigged the 1979 election (Throup and Hornsby 1998: 29).

Kenya had been a *de facto* single party state since 1969, following a brief period of multi-party politics which followed independence, which had ended with the banning of the opposition KPU party (Kenya People's Union) and the detention of its founder, the Luo Odinga Oginga after violent protests against Kenyatta when he visited Kisumu (Gertzel 1970). Following the unsuccessful air force *coup d'état* in 1982 and the attempt in the same year by Odinga Oginga and George Anyona to register an opposition party, a constitutional amendment was rushed through parliament which made Kenya a *de jure* one party state under the ruling party KANU, The Kenyan African National Union (Ogot 1995a: 202). During the 1980's Moi removed challengers to his power<sup>13</sup> and continued to use vote-rigging to secure support. By the end of the 1980's elections were considered farcical and participation in politics had plummeted (Throup and Hornsby 1998: 40-5).

<sup>&</sup>lt;sup>11</sup> I say something about what this means below.

<sup>&</sup>lt;sup>12</sup> Under Kenyatta (1963-78) Kikuyu (members of Kenyatta's own ethnic group) accounted for 29% of cabinet members and 31% of permanent secretaries whereas Kalenjin (an ethnic collation of a number of small groups which included Moi's Tugen tribe) accounted for 6% of cabinet positions and no permanent secretaries. Under Moi (1979-2002), 14% of cabinet positions went to Kikuyu and 14% Kalenjin, but by the end of his regime (1994-2001) only 4% of cabinet positions were held by Kikuyu (against a population of 21%), while 19% of positions were held by Kalenjin (Bangura n.d.) <sup>13</sup> Including Charles Njonjo, a Kikuyu minister with a wide power base which which included senior members of

<sup>&</sup>lt;sup>13</sup> Including Charles Njonjo, a Kikuyu minister with a wide power base which which included senior members of the police, judiciary and civil service, and his associates. (Ogot 1995a: 200-1, Throup and Hornsby 1998: 32-3)

All in all, these actions cemented the move by Moi away from the Kikuyu-Kiambu<sup>14</sup> elite of the Kenyatta era towards a Kalenjin power-base which was strengthened by alliances with smaller ethnic groups, especially the Maasai and the Luhya speaking groups of Western Kenya (Throup 1987, Weinreb 2001a: 450). By the mid- 1980's Moi had become an all-powerful leader who presided over a cabinet whose factions competed to win his patronage and political approval (Throup and Hornsby 1998: 39), in a state where the people's right to choose their political representatives (albeit from within a single party) had radically diminished (Ibid.: 40). This shift was accompanied by a gradual shift in meaning of the term *nyayo* "from 'I (President Moi) will follow Kenyatta's footsteps' to 'follow my footsteps'" (Haugerud 1993: 82).

In hindsight, one might also argue that Moi followed in Kenyatta's footsteps in other ways; by exacerbating grievances over land allocation and ownership that dated back to the colonial era (Elhawary 2009), favouring members of his own ethnic group in government positions (Ochieng' 1995: 102) and civil service employment (Maloba 1995), and through infrastructure improvements in politically supportive constituencies (Barkan and Chege 1989: 449-50). Furthermore, like Kenyatta, Moi presided over a government which was increasingly kleptocratic and authoritarian (Ajulu 1998: 279, Southall 1999: 94); and which was implicated in the high profile assassination of its opponents<sup>15</sup>(Cohen and Atieno Odhiambo 2004, Ochieng' 1995: 101-3, Throup 1987: 50-2, Throup and Hornsby 1998: 58-60, Wrong 2009: 29).

However, the key point that I wish to emphasise here, is that under both Kenyatta and Moi, the Kenyan state was characterised by patron-client relations which functioned as a distributive mechanism for resources which were exchanged for political support. This resulted in unequal distribution of every kind of investment on highly ethnic lines (Berman 1998, Weinreb 2001a, 2001b). As Southall eloquently argues,

"Because the government became the driver of the accumulation process and the most important dispenser of patronage and resources, control over the state became the central preoccupation of politics. Meanwhile, because the (spatial and social) uneven development fostered under imperialism magnified ethnic inequalities, ethnic competition has became the most important mode of political contestation, regulated as under colonialism by authoritarian means" (1999: 93-4).

<sup>&</sup>lt;sup>14</sup> Many of the most powerful ministers in the Kenyatta government were from Kenyatta's home district of Kiambu.
<sup>15</sup> For example under Kenyatta: Tom Mboya, Pio Pinto and J.M. Kariuki. Under Moi: Robert Ouko and Father

Kaiser.

Just as under colonialism when white settlers controlled the assets of the state, the ethnic group and allies of those in power during both the Kenyatta and Moi era were able to gain most in terms of resources of the state, creating continued resentment and tension (Holmquist et al. 1994: 84). I argue that this motif of the state is central to understanding the experiences of Luo people living in Nyanza province, whose people understand themselves as having lost out in terms of resources – those of health care being a prime example – under both regimes, and as continuing to do so under the Kibaki government, since 2002.

Here, Luo people make a comparison not so much with the arid and undoubtedly more impoverished Northern and North Eastern parts of the country, but with those whom, since independence, they see themselves as having been in competition with for political power; the Kikuyu-Meru-Embu groups of Central Province, and the Kalenjin alliance of Rift Vallley. It is to the experience of missing out on 'development' that the popular refrain, "we have not yet eaten the fruits of independence" speaks, emphasising marginality to the state's *resources* rather than a lack of abstract freedoms or human rights. Not that such things are unimportant to Luo people – certainly not to the area councillor in Ramira village who described being tortured in the basement of *Nyayo* house for his alleged involvement in opposition politics in the early 1980's, nor to the family in the same village whose son was burnt alive during the 'ethnic violence' in Coast province in the run up to the 1997 elections; his remains found in a suitcase.

"We have not yet eaten the fruits of independence" emphasises a sense of being peripheral to the state – not so much in terms of its processes, as Luo leaders have since independence played a key role in opposition politics and people's lives are deeply intertwined with the everyday practices and institutions of the state such as schools, hospitals, land registration, police, law courts and so on. Rather the phrase speaks of the sense of a failure of duty on the part of the state and its representatives to adequately transfer the resources of the state to Luo people, and the failure of Luo leaders to position themselves adequately close to the centres of power to channel such resources home. The phrase "we have not yet eaten the fruits of independence" is also an echo of the phrase *Not Yet Uhuru*<sup>16</sup>, the title of the (1967) autobiography of the late Oginga Odinga, who played an important role in opposition politics throughout his lifetime and who is revered by the Luo praise-

<sup>&</sup>lt;sup>16</sup> Uhuru is the Swahili term for independence

name *JaRamogi*<sup>17</sup>. Therefore, to use the phrase can also be to align oneself with a certain (ethnic) political camp.

### A note on ethnicity in Kenya

The complexities of Kenya's different ethnic groups, or 'tribes' to use the often discredited but nevertheless commonly used term (e.g. Atieno-Odhiambo 2002: 230), are such that the topic does not easily lend itself to a 'brief note'. However, it seems impossible to go any further without attempting to explain what it might mean that Moi is a 'Tugen Kalenjin', Kenyatta was a 'Kikuyu' (or 'Gĩkũyũ'<sup>18</sup>) and that my informants in Nyanza were largely 'Luo'.

Ethnic groups in Kenya are understood to 'belong' to certain areas of the country, which are referred to by terms such as 'homelands', through idioms of ownership; 'Luoland', 'Maasailand', and occasionally by older people, in a hark back to the colonial era, as 'reserves'. The creation of administrative boundaries which both mapped and shaped ethnicity and ethnic difference was a key part of the colonial governance project (Lonsdale 1994: 134-5).

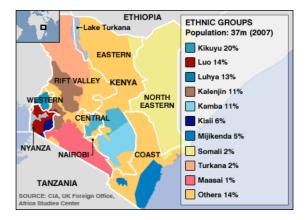


Figure 4. Map detailing the locations of the main ethnic groups in Kenya (BBC News 2008).

Unlike the map above, which suggests an easy division of ethnic difference which corresponds to administrative boundaries, the reality is complex and messy, sometimes violent. As the map shows, Nyanza province, where this fieldwork was carried out, is predominately ethnically Luo, but the map

<sup>&</sup>lt;sup>17</sup> Oginga Odinga is often referred to as *Ker Jaramogi*. Ker is a title given to an important Luo 'cultural' leader (See e.g. Carotenuto 2006). Jaramogi refers to Ramogi Ajwang, the legendary Luo forefather who is said to have founded the first Luo settlement in Kenya (Ogot 1967: 152).

<sup>&</sup>lt;sup>18</sup> Technically, Kikuyu refers to the language. Kikuyu is the anglicised form of Gĩkũyũ which refers to the people, although they refer to themselves as Agĩkũyũ. However, the term Kikuyu is commonly used for both in contemporary Kenya, by both Kikuyu and non-Kikuyu people. I follow this convention here.

does not for example, show any of the smaller minority groups, such as the Suba, who also live in the province. The areas on the map marked 'others' are either populated by a number of smaller ethnic groups or are ethnically mixed. Mixed areas include Nairobi and parts of the fertile Rift Valley and Mount Elgon areas (seen stretching between Central Province to the Ugandan border) which have been the sites of brutal ethnic violence over the last 15 years, including in the period following the 2007 elections which took place after this fieldwork was completed. The language map below points to a more complex ethnic mixture in the country even if it does not do justice to the lived experience of ethnicity in Kenya:

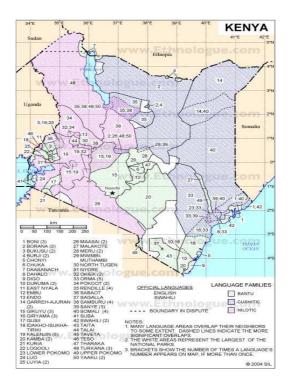


Figure 5. Language Map of Kenya (Gordon 2005)

Some of Kenya's 'tribes', such as the Kalenjin and Luyha are not so much single ethnic groups as a collection of smaller groups (including Moi's Tugen group) (Lynch 2006: 236-7, Wrong 2009: 49), whose 'native homelands' and 'tribal identities' are colonial 'inventions'; that is a product both of colonial control and imagination as well as African responses to the changing opportunities and restrictions of the colonial (and post-colonial) era (Berman 1998, Ranger 1983). John Lonsdale, an influential social historian on Kenya, is worth citing at length here on colonial governance in Africa;

"Colonial governments had to police internal boundaries to restrict movement; but in thus stopping tax evasion they also encouraged local loyalties. By supporting client chiefs with

the rituals and rules of 'customary' law, they crystallised and thus hallowed ethnic legal traditions. White missionaries simultaneously invented standard tribal languages out of a mass of sub-ethnic dialects. White employers stereotyped migrant workers by their presumed tribal aptitudes for different sorts of work...Geographical differentiations in soil, rainfall and access to markets dictated that some would become cocoa tribes, or cotton, clerical or mine working tribes. In reaction, Africans made the identities which Europeans had wished upon them live, instead, for themselves. They found that tribes made excellent producer co-operatives or Trades Unions'' (Lonsdale 1994: 134-5; See also Holmquist et al. 1994: 72-4, Ranger 1983).

As Atieno-Odhiambo (2002: 230) argues, ethnicity for Kenyans is not the "ambiguous" category that it is for academics, but rather tribalism, which holds a set of meanings which come from lived experience rather than scholarly reflection, provides a "practical vocabulary of politics and social movements", providing context to everyday experiences of both enablement and restriction, with a capacity equally for violence, support, and legitimate democratic advancement. The category Luo is thus an important and meaningful one for those who use it to describe themselves. For such reasons I also continue to employ the category Luo in the descriptions and analysis of this thesis.

#### Health care in the first nyayo decade: unequal distribution of resources

Because tribes have made an excellent basis for gaining and maintaining political support by tactically distributing the resources of the state, politics in Kenya has become characterised by a patron-client system understood by the powerful metaphor of *eating* (e.g. Bayart 1993, Wrong 2009). In this metaphor, which can become a matter of fact as people watch those with access to the resources of the state literally become fatter, the relation of society to the state is seen as one of eating the state's assets. This is particularly true of health care provision, which has been, with education, one of the most far reaching interventions of the state since independence.

The ethnic dimension of these networks of distribution and patronage is such that, "even as they ritually denounce 'tribalism', African politicians, in the open secret of African politics, sedulously attend to the maintenance of the ethnic networks of patronage that are the basis of their power" (Berman 1998: 306). In such a system, it is understood that leaders will also 'eat', but that, "in exchange for the opportunity for personal enrichment, representatives are expected to direct some of the state's resources to their area. Their clients expect to see development funds" (Weinreb 2001a: 444).

Improving health care was a major priority of Kenya's first independent government. Interventions included building a national medical school, replacing expatriate doctors and nurses with trained Kenyans, building dispensaries for the rural population and increasing the number of health facilities. However, despite the progress made during the Kenyatta era, little headway was made in reducing the disparities of coverage across different provinces that had become established during the colonial era, and Nyanza province remained under-resourced compared to other provinces (Maxon 1995: 132-5).

This trend continued into the Moi era. For example, Table 1, below, shows that in the middle of the 1980's Nyanza province received a much smaller proportion of health investment in relation to population size than the areas of the country which supported Moi. The differentiation would be even greater if we were to compare expenditure to disease burden, as Nyanza province has suffered disproportionately from many diseases, particularly malaria and in more recent years HIV/AIDS. What one sees in this table is Moi's supporters benefiting from state investment, while his opponents, the Kikuyu of Central Province and the Luo of Nyanza Province do badly. If one includes Western province in the Moi power base as well as the Rift Valley, we see those areas which supported Moi at this time benefiting from 57% of rural health investment against a population of 33%.

However, while the figures presented provide support for the discourse of unequal distribution in some regards, they also show how the discourse of Nyanza 'missing out' discounts both the experience of the Kikuyu under Moi (as they are assumed to have had their chance to 'eat' under Kenyatta) and those who live in the politically marginal North and North Eastern provinces.

PROVINCE	POPULATION (%)	HEALTH EXPENDITURE (%)
Central	15	10
Coast	9	12
Eastern	18	8
North-East	2	3
Nyanza	17	5
Rift Valley	21	32
Western	12	17

#### Table 1. Provincial Shares of Development Expenditure for Rural Health 1987-8 (Barkan and Chege 1989: 449)

# Kenya under Moi in the 1990's: Structural adjustment, multiparty politics

Economically, things grew increasingly bad for Kenya during the 1980s and 90s. The Kenyan economy had grown at an impressive rate in the first 10 years following independence (1963-73), but by the end of the 1970s economic growth had slowed and Moi took over an ailing economy from Kenyatta. A large state sector and an extensive network of patronage became increasingly difficult to maintain as the economy shrank (Holmquist et al. 1994: 91), especially given that the clients of the Moi regime tended to be relatively impoverished and peripheral to capitalist development in comparison to Kenyatta's Kikuyu clients (Ajulu 1998: 279-80).

Lack of funds with which to maintain extensive networks of patronage is probably one of the reasons why the Moi government became increasingly kleptocratic (Ajulu 2001: 199), with the government and its cronies implicated in scams to steal greater and greater sums, such as in the infamous Goldenberg scandal (Warutere 2005). Meanwhile, Moi was ambivalent about nurturing economic sectors (some of the most prosperous in the country) which would give Kikuyu people more economic clout (Throup and Hornsby 1998: 48). In addition to this, the population of the country had almost 36 quadrupled in the period between Kenya becoming independent and the late 1980s putting additional strain on limited resources (Throup and Hornsby 1998: 47).

Throughout the 1980s, in an effort to deal with the deteriorating economy, the Kenyan government signed a series of structural adjustment loans mostly financed by the World Bank, increasing the country's external debt servicing charge ten-fold between 1974 and 1993 (Mosley 1991, Mwega and Kabubo 1993: 28). In health terms, the percentage of GDP spent on health decreased from 2.3% in 1981 to 1.7% in 1985 and 1990 (Swamy 1996: 205).

The first structural adjustment loan contracted to finance health reform was in 1988. As one of the conditions of the loans, user charges for outpatient and inpatient care, known as 'cost sharing' were introduced (Swamy 1996: 228). The Kenyan government did not comply with many of the conditions of world bank loans (e.g. Mosley 1991), but did introduce these highly unpopular user fees, which were a fiasco (Booth 2004: 109-110). In the first instance, the introduction of fees was accompanied by a drop in attendance at government health facilities of over 50% in some areas. The government removed the fees for a period of 20 months in response to a media campaign against the charges (Mwabu 1995: 252) during which attendance increased by 41%, and then reintroduced cost-sharing in 1992 (Mwabu et al. 1995). Cost sharing subsidies exist in Kenyan hospitals up to the present day.

Economic difficulties were an important factor behind growing calls for democracy in the late 1980's (Haugerud 1993: 17, Holmquist et al. 1994: 96-9). In December 1991, after a period of growing pressure from civil society and opposition politicians for democratic reform, civil unrest (Atieno-Odhiambo 2002: 229), international pressure (Throup and Hornsby 1998: 84), and popular discontent, Moi was forced to announce the repeal of section 2(A) of the constitution which banned opposition parties (Ogot 1995b: 239-45, Throup and Hornsby 1998: 54-88). However, the move towards multiparty politics did not lead to the opening of more democratic spaces in Kenya. On the contrary, freedoms of the press, opposition politicians and activists and the independence of the judiciary were further curtailed. Meanwhile, the 1992 and 1997 elections were rigged in favour of the ruling party, KANU (Adar 2000, Ajulu 2001: 197, Brown 2001), partly through the use of government orchestrated 'ethnic' violence (Adar 2000: 116-9, Brown 2001: 727-8).

# AIDS policy under Moi (1985-99): Accusations and denial

It was therefore into a chaotic and corrupt political environment and economic gloom that the AIDS crisis in Kenya unfolded. In January 1985 the Kenyan press first reported on probable AIDS deaths in

Kenya and in September of the same year the Kenyan Ministry of Health unofficially let it be known that 20 victims of AIDS had been diagnosed in Kenya in the previous 4 months (Fortin 1987: 907-8). International reports of 'AIDS in Africa' gained momentum. The Kenyan government, anxious to protect its growing and profitable tourist industry and angered by the racist undertones of such reports, responded with denial (Booth 2004: 17, 52, Ogot 2004: 9, 11, Sabatier 1988: 113-4) and silence (Nzioka 1994). The national press claimed that reports of AIDS in Kenya were "alarmist and untrue", and President Moi described articles in the foreign press as a "hate campaign" and ordered the burning of copies of a November 1985 issue of the *Herald Tribune* which suggested that the AIDS virus began in Africa (Fortin 1987: 908, see also Ogot 2004: 12-3; 31-3).

Booth describes in some detail the early years (1986-93) of AIDS policy in Kenya and the rise and fall of the World Health Organisation (WHO) collaboration with the Kenyan government to fight AIDS. Her description emphasises the role of the WHO as the most important strategic partner and conduit of funds to fight AIDS in Kenya in these early years, via a mode of intervention into the HIV/AIDS pandemic which was premised on the role of the nation-state as the "appropriate arbiter of what should be done to improve or protect its population's health" (2004: 59). In an approach which was very similar to the one which the WHO was administering in other countries around the world during this period (Barnett and Whiteside 2006: 79), the WHO collaboration with Kenya created a framework for HIV/AIDS intervention within which an umbrella organisation would supervise and coordinate the activities of agencies from all sectors. This organisation was to become, in 1987, the National AIDS Control Programme or NACP (Booth 2004: 63-4).

NACP's first medium-term plan for the sector prioritised establishing a safe blood supply; developing a set of AIDS guidelines for health care professionals; and educating the Kenyan public on modes of transmission, through a campaign known as 'Crush AIDS', which became the face of AIDS prevention throughout the 1990's. The emphasis of the campaign was completely on prevention and it was only in later years that government policy began to emphasise care of people living with HIV/AIDS;

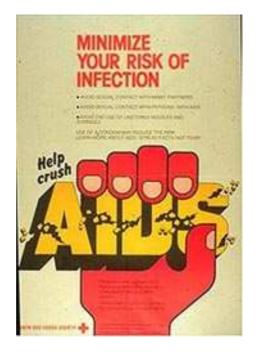


Figure 6. Poster for the "Crush AIDS" campaign (Ministry of Health and Kenya Red Cross 1991)<sup>19</sup>.

In 1987, the NACP was merged with the STD Control Programme to form NASCOP (National AIDS and STD Control Programme), based in the Ministry of Health (Wambuii 2006: 61). Despite these moves towards a comprehensive AIDS policy, Booth maintains that a culture of denial persisted throughout the 1990's during which,

"President Moi was unwilling to speak out about AIDS or safer sex, publicize accurate statistics on the spread of the virus, create a budget dedicated to AIDS control, protect stigmatized groups, or acknowledge the existence or struggles of Kenyans living with AIDS" (2004: 17).

Elsewhere, Fortin argues that legitimate concern about the stigmatising, discriminatory nature of the links that were being made between Africans and AIDS (a process that Cindy Patton (1990) would later describe as the 'invention' of African AIDS) went alongside attempts by many African governments to restrict the sharing of information on AIDS and the conduct and publication of research on AIDS (Ibid.: 909-10). He maintains that it is likely that the Kenyan government underreported AIDS deaths during these early years (Fortin 1987: 912) Similarly, Booth describes as

<sup>&</sup>lt;sup>19</sup> The poster reads, "Minimize your risk of infection: Help crush AIDS. Avoid sexual contact with many partners. Avoid sexual contact with persons with AIDS. Avoid the use of unsterile needles and syringes. Use of a condom may reduce the risk. Learn more about AIDS: Spread facts not fear."

"contradictory" the early Kenyan response to AIDS, because of the way government denial went alongside the relatively speedy formation of a National AIDS committee.

In the meantime, the AIDS crisis was growing in Kenya and increasing numbers of people were becoming infected with the disease (e.g. Cheluget et al. 2006: i23, fig. 4). Internationally there was wrangling between the WHO and the UN over who should remain the lead agency in the fight against AIDS which resulted in a change of leadership within the WHO. Meanwhile in the Kenyan context there were increasing difficulties in the relationship between Moi and donor agencies, caused by concerns about corruption and misuse of resources (Booth: 2004: 68-70). Booth argues that the result was near inertia in terms of AIDS policy during this period, in terms of both definition and delivery Booth (Ibid. 2004: 74-7).

All this took place in the context of a woefully underfunded Ministry of Health, whose budget for 1995-6 was equivalent to \$5 per Kenyan, and thereby half what it had been in 1980-1, of which 70% was required to fund salaries so low that many Ministry employees had started private clinics which they ran in parallel to their Ministry jobs or had left the Ministry altogether to more lucrative employment in the private sector or overseas<sup>20</sup> (Hearn 1998: 91).

The Kenya AIDS NGOs Consortium (KANCO), which had grown to over 320 members, was complaining of little effort to deal with HIV/AIDS despite a sharp spike in prevalence (Ogot 2004: 57). All in all, the combination of growing economic hardship, dwindling donor funds through the WHO, the harsh conditions of IMF loans (especially those which required cut-backs in health services), civil unrest, political violence and enduring prejudice and stigma around AIDS exacerbated the epidemic throughout the 1990's. Government and NGO efforts did little to stem the rising prevalence of HIV/AIDS during the 1990's, especially in Western Kenya where the epidemic was most severe<sup>21</sup>:

<sup>&</sup>lt;sup>20</sup> A pattern repeated in other African countries. See e.g. (Kyaddondo and Whyte 2003).

<sup>&</sup>lt;sup>21</sup> I discuss the reasons why this was the case in the next Chapter.

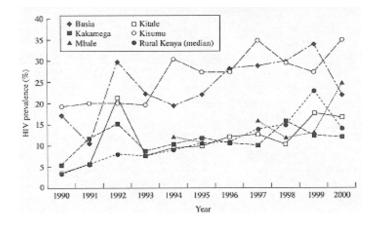


Figure 7. Antenatal HIV prevalence in sentinel surveillance sites in Western Kenya 1990-2000 (Moore and Hogg 2004: 545).<sup>22</sup>

# AIDS as a 'national disaster' (1999-2002): NACC, PACCs, DACCs and CACCs

"AIDS is not just a serious threat to our social and economic development, it is a real threat to our very existence...AIDS has reduced many families to the status of beggars...no family in Kenya remains untouched by the suffering and death caused by AIDS," President Moi, *opening remarks at a national seminar on HIV/AIDS, Mombasa, October 1999* 

When Moi declared AIDS a national disaster in October 1999, he simultaneously announced the creation of the National AIDS Control Council (NACC) to combat the disease, which would coordinate all AIDS activities and reflected the growing understanding of AIDS as a multi-sectoral problem, not merely a health issue (Wambuii 2006: 62-3). The NACC was an example of the organisational template that was favoured by the WHO during the 1990's and has more recently been pursued by the Global Fund and PEPFAR, which involves a high-level HIV/AIDS coordinating body organising a multi-sectoral approach with a separate mechanism for coordinating responses to the disease within the Ministry of Health (Putzel 2004).

 $<sup>^{22}</sup>$  The rural sites of Kagot and Ramira lie more or less equidistant between Busia and Kisumu. There is a great deal of controversy over HIV prevalence statistics in Kenya which revolves around their accuracy, the ability to extrapolate ante-natal data to the population more widely and so on. These debates fall outside the scope of this thesis and I ask only that this information be used to show general trends of HIV prevalence.

Although there was considerable influence from global organisations, especially the WHO, to design particular kinds of response to HIV/AIDS, policy responses to the epidemic in sub-Saharan Africa were heterogeneous in their organisation and implementation (Dickinson and Buse 2008) and the Kenyan response was frequently held up unfavourably against what was understood to be the more open and successful approach taken in neighbouring Uganda (e.g. Nzioka 1994: 170-1)<sup>23</sup>. In 1999, Moi's remarks and actions were seen by AIDS activists as coming a decade too late and he was widely criticised in Western media for his failure to endorse condom use as a preventive measure in the spread of HIV (e.g. BBC News 1999, Reuters NewMedia 1999)<sup>24</sup>.

Whilst the Kenyan government continued its indecisiveness and lack of action regarding the promotion of condoms and an HIV/AIDS curriculum for schools, money to fight AIDS began to flow into Kenya; \$100 million came from the World Bank for the period 2001-5 while the NACC 2001 audit showed contributions including \$17 million from DFID, \$11.5 million from USAID and \$15 million from UNDP, giving the NACC an annual budget for 2000-1 which was equivalent to 25% of the Ministry of Health's entire budget for the same year (Ogot 2004: 92).

The NACC became part of a huge unwieldy bureaucracy. Initially there was controversy over its location within the national Office of the President, rather than within the Ministry of Health, a controversy largely seen as a fight between those who wished to control its resources. Meanwhile, the NACC's constituent parts; the Provincial AIDS Committees (PACCs), District AIDS Committees (DACCs) and Constituency AIDS Committees (CACCs) (see e.g. Ministry of Health 2001: 30-33) created an unashamedly bloated mechanism for addressing the pandemic. Such huge sums were spent on meetings and seminars at all levels, that the proliferation of acronyms and the hundreds of new NGOs and community organisations that sprung up to relieve the NACC, PACCs, DACCs and CACCs of their new funds, became a subject which would have bordered on the comical<sup>25</sup>, were it not for the fact that funds were not reaching those who most needed it; the epitome, perhaps, of a sick joke. Instead, AIDS funds and bureaucracies became part of the huge patronage machine through which the state maintained its power (Ogot 2004: 83-8, 96-9).

<sup>&</sup>lt;sup>23</sup> I frequently heard comparisons which praised the Ugandan response over developments in Kenya when working for a small Kenyan NGO in 2000-1.

<sup>&</sup>lt;sup>24</sup> The promotion of condoms had been a difficult issue for the Kenyan government throughout the Moi era (for example see Ogot 2004).

<sup>&</sup>lt;sup>25</sup> This was certainly my experience of talking to AIDS activists and community workers at the time in Western Kenya.

And there were so many who needed it. By 2000, Kenya had a national prevalence of 14% (the 5<sup>th</sup> highest in the world), but a prevalence topping 35% in the worst hit areas (Cheluget et al. 2006: i23), and over 2.2 million living with HIV (Ogot 2004: 88). In 2000-1 the hospitals I visited in the Nyanza region were generally overcrowded and often lacked basic equipment and medicines for treating opportunistic infections. Across Kenya there were very few sites where HIV tests were available<sup>26</sup> and test results were neither immediate nor reliable. People who 'showed the signs of AIDS' complained that if they visited hospital they were treated harshly by health workers and sent home with only aspirin. In villages, abandoned homes of the dead crumbled. In some cases, long grass covered whole compounds where many families had once lived. For the rich, AIDS was changing from a terminal illness to a chronic condition as people gained access to anti-retroviral therapy, available in the West and increasingly in Nairobi at great expense. Yet it seemed unlikely that these medicines would ever be within the reach of the majority of people of Nyanza province, although there were those who stayed alive in prayerful hope that such a day would come. For far, far too many people, that day did not come soon enough.

# ARVS come to Kenya

In the last years of the Moi regime, as commentators were drawn into a 'will he won't he' debate about Moi's announcement not to seek a third term (Ajulu 2001, Southall 2000), there were the beginnings of significant shifts in HIV care in Kenya. Globally, important developments in debates around HIV care and ARVs were ongoing, centring around the divergent issues of intellectual property and patent rights over ARVs; the right of those living with HIV/AIDS to health and treatment; and the question of whether ARVs could be successfully administered in so-called "resource-poor settings" (Barnett and Whiteside 2006: 365-9).

Many questioned the morality of the large pharmaceutical companies who sold many of the antivirals used against AIDS at higher prices in the poorer developing world than elsewhere and who seemed determined to keep their copyrights of AIDS medication although they had already recouped their development costs many times over and when these costs had partly been covered by government research grants in the first place (Ogot 2004: 103-6, Poku 2002: 292-4). In South Africa, an activist group called the Treatment Action Campaign launched a highly visible struggle for access to medication, which among other achievements, forced 39 drug companies who sued the South African government for breach of drug copyright in 2001 to drop their case for the protection of

<sup>&</sup>lt;sup>26</sup> As elsewhere, until the development of rapid test kits.

patents on ARVs (Friedman and Mottiar 2005, Robins 2004). Although in theory this court case opened the doors to the development of cheaper generic ARVs world-wide, in Kenya the government resisted pressure from NGOs influenced by groups such as the Treatment Action Campaign in South Africa and refused to come out squarely against the international patent system to begin importing generic copies of ARVs. Complaints grew that some MPs were in the pockets of Kenyan based multi-national pharmaceutical companies and were working to scupper moves towards the legalisation of the import of generic HIV drugs (Ogot 2004: 101-7). Meanwhile, the world watched with interest the development of an implementation model pioneered in Brazil which combined prevention with ARV treatment as an example of how ARVs could be administered in poor and middle-income countries (Biehl 2005: 249-51, 2007).

The Kenyan government finally passed an Industrial Property Bill in 2001 which allowed for the manufacture and importation of generic HIV drugs, but dragged its feet on the implementation of the bill which did not become effective until September 2002 (Ogot 2004: 112, 114-5). This was some three months before the general election in which Moi's KANU party lost power for the first time since independence. There were no plans at this time to introduce wide-spread access to ARVs from within government facilities. However, the first patchy supplies of anti-retroviral drugs had begun to arrive in Kenya, including Nevirapine, donated to prevent transmission of the HIV virus from mother to child during pregnancy and childbirth, an intervention which it was predicted could reduce mother to child transmission of HIV by more than 50% (Ogot 2004: 114, Wambuii 2006: 73).

#### 'Total war on AIDS': the Kibaki government from 2002

"To further intensify the war against HIV/AIDS, my government has launched a new initiative known as Total War Against Aids. The objective is to further reduce the HIV/AIDS prevalence to below 5.5 percent by the year 2009. As part of this initiative, we will continue to increase the number of people on Anti-Retroviral therapy and also provide socio-economic safety nets for those infected and affected. I urge all Kenyans to observe safe behaviour in order to keep the disease at bay" Mwai Kibaki, *Jamhuri* Day Speech 2005.

Those who doubted that Moi would ever leave office or allow KANU to lose an election (e.g. Ajulu 2001) were finally proved wrong in December 2002, when Mwai Kibaki was elected President of a broad coalition group known as NARC (The National Rainbow Coalition), on an anti-corruption and democratic governance platform. The opposition had buried their differences and united behind 44

Kibaki against Moi's choice of candidate, Uhuru Kenyatta (the son of Kenya's first president), who was widely considered to be too young and inexperienced to lead Kenya (Barkan 2004) and whom Moi himself admitted would be the easiest candidate to "guide" (Brown 2004: 330-1). In Nyanza, and around Kenya, the charismatic Luo leader Raila Odinga helped persuade voters<sup>27</sup> to support Kibaki, a Kikuyu, with rallying cries of *Kibaki Tosha!* (Kibaki is enough!) and *Unbwogable!* (A *sheng*<sup>28</sup> combination of Luo and English meaning un-frighten/beat-able).

After NARC's victory the mood was jubilant (Murunga and Nasong'o 2006, Wrong 2009: 1-8); Kenya was found to be the most optimistic nation in the world in an opinion poll three months after the December 2002 elections and people chanted *yote yawezekana bila Moi!*; "Everything is possible without Moi!" (Murunga and Nasong'o 2006: 1-2). The optimism was infectious, not just among Kenyan *wananchi* (Swa. general public), but also among some academic commentators who began to speak positively of "new forces shaping Kenyan politics" (Barkan 2003). I was told stories of passengers on *matatu*, the infamously dangerous minibuses providing public transport across the country, who, swept up in the tide of change, would ring an anti-corruption hotline on their mobile phones to condemn touts who had breached the rules on the maximum number of passengers, had paid a bribe to police officials, or had tampered with the speed control on the vehicle.

However, just over two years after the NARC victory, some 61% of Kenyans thought life was worse than it had been under the previous regime (Murunga and Nasong'o 2006: 5). Kibaki had thrown out the memorandum of understanding between the leaders of the NARC coalition, appointed his own cronies to cabinet (mostly Kikuyu and their Embu and Meru allies), reneged on the deal that a position of Prime Minister would be created for Raila Odinga and stalled on constitutional reform (Brown 2004: 334, Lynch 2006: 242, Murunga and Nasong'o 2006: 14-8, Steeves 2006: 204-5). The NARC coalition looked unstable, but Kibaki prevented the opposition from uniting against him by offering sweeteners in the forms of less prestigious cabinet positions and ministry portfolios to less powerful opposition leaders, while Kikuyu held all the leading positions both in government and the civil service (Murunga and Nasong'o 2006: 10-11, Steeves 2006: 205).

<sup>&</sup>lt;sup>27</sup> Especially Luo voters (Lynch 2006: 255).

<sup>&</sup>lt;sup>28</sup> Sheng is a term for a kind of slang used in Kenya, especially in Nairobi, which mixes together mostly English and Swahili to create new words, and also commonly used words from some of the other languages spoken in Kenya, particularly Kikuyu and Dholuo, which are the most widely spoken languages in Kenya after English and Swahili.

Fissures began appearing between Kibaki's group and other ministers, especially Raila Odinga and Kalonzo Musyoka (Lynch 2006: 241), long before the constitutional referendum on 21<sup>st</sup> November 2005. Although there had been a substantial power shift in Kenyan politics away from the Kalenjin elite to a group of Kikuyu politicians who became known as the 'Mount Kenya Mafia', many of whom were old-timers who had played a central role in the Kenyatta regime, this was the only real change that NARC brought to Kenya. In terms of the mechanisms of state patronage and corruption it was a case of more of the same, and many would argue, worse. Murunga and Nasong'a argue that the combination of the Kibaki regime's complete failure to punish any of those implicated in corruption scandals under Moi went alongside new and blatant corruption which unfolded under the Kibaki premiership. This included the Anglo-Leasing scandal, where millions of Shillings were spent on contracts with fictitious companies. They argue, "[I]f former President Moi followed Mzee<sup>29</sup> Jomo Kenyatta's footsteps in institutionalising corruption, then Kibaki is more 'Nyayo' than Moi" (2006: 20, 19-22).

In terms of HIV/AIDS policy, it was also more of the same. In-fighting over control of funds and controversy over the promotion of condoms continued (Ogot 2004: 116-8). Just as they did in other areas of public life, allegations of corruption soon began to surface around NACC (Ogot: 89-93; 95; 125) and in 2003, the director of NACC, Margaret Gachara, was sacked and eventually imprisoned (although not ordered to repay the stolen funds) for defrauding NACC of 27 million KSH<sup>30</sup>(Daily Nation 31st August 2004).

# Oranges and bananas: The NARC falls apart

Tensions grew within the shaky coalition government in the run-up to the November 2005 constitutional referendum. MPs close to the President began commenting that a constitutional change may no longer be necessary, given that Kenya now had a 'good' president. The events leading up to the creation of the Wako draft of a new constitution were complex, but can be broadly glossed as follows: calls for constitutional review led to the development, over some years but completed in 2004, of a 'Bomas draft' constitution (so-called after the place where it was written), widely considered to be broadly 'popular'. Kibaki and his supporters then voted to amend the Constitution of Kenya Review Bill in parliament, which allowed them to change the Bomas draft with a simple (rather than two-thirds) majority. Attorney General Amos Wako was mandated to come up with a

<sup>&</sup>lt;sup>29</sup> A respectful Swahili term meaning old man.

 $<sup>^{30}</sup>$  At the time equivalent to around £250,000

final draft based on the Bomas draft combined with suggested (i.e. by Kibaki and his supporters) amendments.

The Wako draft, unlike the Bomas draft, did not curtail the presidential powers by creating a ceremonial president and this became a central campaign message of the 'No' campaign, (Lynch 2006: 238-40, Steeves 2006: 207). The Cabinet split into 'Bananas', supporting Wako and led by Kibaki, against 'Oranges', who included a number of Kibaki's cabinet members and who were joined by a majority of the KANU MPs who formed the official opposition. At the polls, 57% of voters rejected the Wako draft, with the orange team winning a majority in every district except the predominately Kikuyu central province (Lynch 2006: 234).

Such was the political situation late in 2005, one week after the constitutional referendum and some twenty years after the first cases of AIDS were identified in Kenya, when I arrived in Kisumu with my partner and our young son to begin fieldwork. Everywhere was talk of politics; newspapers – each one already read by perhaps twenty or thirty people as they were passed around shoe shiners, offices, staff rooms and every other middle-class location – were even more highly sought after than usual as people tried to second guess Kibaki's next move. In Kisumu, many people celebrated what they saw as a national vote of no confidence against Kibaki and the enduring corruption of the NARC regime, others showed only their relief that violence had not followed the referendum<sup>31</sup>. Kibaki finally reacted by dismissing his entire cabinet and announcing that parliament would be on recess until March 2006, thus giving himself chance to avoid a real vote of no confidence.

### Care in Kenyan AIDS policy from 2003: The arrival of the 'big three'

Within this tumultuous political climate, huge changes were taking place in HIV care in Kenya and across sub-Saharan Africa. New sources of funding were changing the organisation and priorities of HIV care, based upon the assumption that the problem of how to deal with AIDS was not lack of knowledge about the disease and appropriate interventions but rather resources (Green 2003).

The first meeting of the Global Fund to fight AIDS, Tuberculosis and Malaria (hereafter the Global Fund) had taken place in January 2002. The Global Fund would be, it was argued, a new kind of global

<sup>&</sup>lt;sup>31</sup> There had been violence in Kisumu in the run-up to the referendum when the banana camp held a rally to garner support for the yes vote. Young people began to protest and the police opened fire on the crowd killing three, including a child. Another person died the following day (Daily Nation Friday 4th November 2005). However, the referendum had passed off peacefully. It was only after the 2007 elections that I realised how well placed this gratitude was.

initiative with the Global Fund working as a "hands off" entity providing funding but not technical assistance with programmes coordinated by in-country organisations (Bernstein and Sessions 2007: 8, Garmaise 2009, McCarthy 2007), professing three commandments; "Raise it, Spend it, Prove it" (Pisani 2008: 296). Meanwhile, the World Bank announced a huge expansion of its MAP (Multi-Country AIDS Programme). Also, in January 2003, President Bush announced the US initiative which would become PEPFAR, committed to spending \$15 Billion dollars over five years (Green 2003, Pisani 2008: 33-4; 192). Large proportions of the funds from these initiatives were allocated to the provision of care and the roll out of ARVs. In the same year the WHO announced a plan to treat 3 million HIV+ people with ARVS by the end of 2005 (WHO 2003). Huge sums of money were involved:

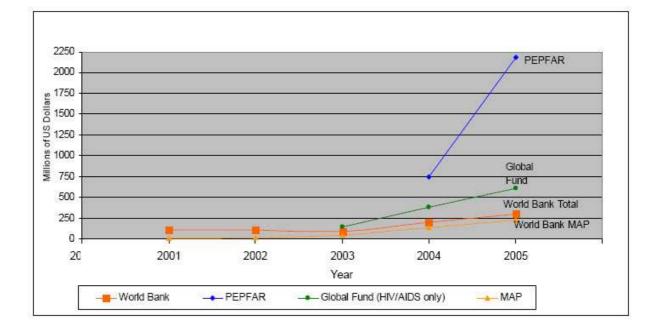


Figure 8. Annual amounts dispersed by 'the big three', 2001-5 (Bernstein and Sessions 2007, see also Pisani 2008-4; 192; 269-70).

In Kenya, care of people with HIV/AIDS had been written into policy documents since the late 1990's, but little had been done in terms of tangible improvements in services for HIV patients through government facilities. By far the majority of care work was undertaken by families (Iliffe 2006: 102), alongside hospital admissions of varying lengths of time, even when sick people were enrolled in Home-Based Care programmes. In terms of ARV provision and HIV care generally, Ogot argues that despite a plethora of plans, policies and strategies, the NARC government had not seriously

addressed the issue of clinical provision by 2003. However, Kenya was not alone in this; when the WHO launched the 3 by 5 initiative in 2003 to treat 3 million people with ARVs by 2005, only 8% of the estimated 6 million in the developing world in need of treatment were receiving it (WHO 2003: 4). In Kenya at this time the total number of people receiving ARV therapy numbered less than 20,000 people, most of whom were being treated in mission or NGO clinics (Ogot 2004: 119-121). The arrival of the big three changed this, but coverage remained limited to District centres and large hospitals<sup>32</sup>, placing a heavy burden of transport costs on some patients. Meanwhile, although the Kenyan government stopped charging for ARVs in March 2005, HIV care sometimes involved hidden costs to patients (see Chapter 5).

However, these developments changed the Kenyan HIV care strategy immeasurably. In the 2001 government report on "AIDS in Kenya", the solution offered by the Ministry of Health to the growing burden of providing care to people with AIDS had not been to increase services, staff or begin delivery of ARVs (then considered prohibitively expensive), but rather that "AIDS must be controlled" (Ministry of Health 2001: 18-20). By 2005, in an updated report, the Ministry of Health wrote, "The focus of programme interventions has shifted from general prevention and supportive care to more specific health services such as testing and counselling and antiretroviral treatment" (Ministry of Health 2005a: vii). The 2005 report is a completely different document from that of 2001, outlining complex and developed strategies for dealing with HIV/AIDS rather than simply detailing the problems caused by the disease. The report describes plans for the progressive delivery of ARVs (Ibid.: 51) and talks of the integration of PMTCT (Prevention of Mother to Child Transmission), TB treatment and VCT (Voluntary Counselling and Testing) into comprehensive HIV/AIDS care (Ibid.: 57, 59, 69).

In Kenya, the US health agency Centers for Disease Control (CDC) had signed a co-operative agreement with the Kenya Medical Research Institute (KEMRI) and was by 2005 taking the lead in a complex combination of research and resource provision in a large part of Nyanza province where it had a large "field station". In Kagot District Hospital, the new VCT (voluntary counselling and testing clinic) and PSC (Patient Support Centre – for "comprehensive HIV care"), a more-or-less constant supply of HIV rapid test kits; trained peer counsellors and a PMTCT (prevention of mother and child transmission) department with two full time nurses and two counsellors were the most tangible signs

 $<sup>^{32}</sup>$  Indeed initiatives such as the 3 x 5 initiative were only ever expected to a step towards universal coverage (WHO 2003)

of the new funding priorities. Across the district a growing number of 4x4 vehicles could be seen criss-crossing the region carrying blood samples for CDC and ferrying NGO workers to seminars and awareness raising meetings.

As long ago as 1989, Cindy Patton used the term 'AIDS Industry', to describe the shared vision, practices and relationships between the governmental and non-governmental AIDS organisations in the United States. Patton was keen to work with this notion of industry, in the sense of collaborative work, to consider how AIDS came to be constructed as a particular kind of disease meriting particular interventions through a specific set of roles (Patton 1989). With the arrival of the big three, later joined by others such as the Gates Foundation, the term AIDS Industry has taken on a more sinister connotation (e.g. Pisani 2008) that is suggestive of large contracts for international experts, four-wheel drive vehicles crossing rural Africa blowing dust on the poor and local responses to the influx of funds, such as the building of new hotels in the last five years to host AIDS seminars<sup>33</sup>. This thesis is in part an ethnographic documentation of this early period of ARV intervention and the intersections between government health policy, the organisation of resources, new economies of care and the experience of managing illness and suffering, from the perspective of one high-impacted location within Western Kenya.

<sup>&</sup>lt;sup>33</sup> I am grateful to Susan Pietrzyk for raising my attention to a shift in critiques of the AIDS Industry from a more ideological critique around a lack of funding/resources (80s-90s) to (post-2002) a critique of a wasteful bureaucracy, via the discussion forum of the AIDS and Anthropology Research Group.

# Chapter 2. Home and Hospital as Domains of Care

In the previous chapter I gave an account of the political and economic context within which HIV/AIDS policy in Kenya has developed since the beginning of the epidemic. In this chapter I turn the focus to the more specific context of Kagot District. I begin by summarising some of the debates as to why Luo people in Nyanza have suffered disproportionally from the HIV/AIDS epidemic. I then turn the discussion to an introduction of the three key themes of the thesis; care, home and hospital.

#### 'Culture problems': Discourses on HIV prevalence in Western Kenya

"The AIDS epidemic is simultaneously an epidemic of a transmissible lethal disease and an epidemic of meanings or signification" (Treichler 1999: 11).

"We started Kagot Development Group because we saw the people were suffering. This is an AIDS region. Here people are dying. Even if you stay here you will see coffins passing" (Philomena Nyamogo, 1<sup>st</sup> November 2007).

National HIV prevalence in Kenya has been measured through antenatal surveillance since 1990 and through two national surveys carried out in 2003 (Central Bureau of Statistics et al.) and 2007 (NASCOP). With improvements in data collection and methods for measuring prevalence, estimates continue to be revised over time (e.g. NACC and NASCOP 2009). Considerable debate exists over the reliability of such estimates both from an epidemiological perspective (e.g. Strickler et al. 1995) and in the popular Kenyan press (e.g. Daily Nation July 6 2006). However, whilst estimated prevalence rates may not provide an exact picture of prevalence, they do have very real effects in terms of the organisation of responses to the disease (including the growing presence of researchers in the region), in addition to shaping discourses which link high levels of HIV with 'Luo culture'.

Based upon the combined data of the sentinel and the national surveys, prevalence for the district which I call Kagot was estimated to be 29% in the 2006 district development plan; a figure written in bold lettering alongside other statistical information about the district in the administrative offices of the District Hospital. This estimate stands against a 2007 provincial average of 15.3%, itself double

the national prevalence rate of 7.8% (NASCOP 2007)<sup>34</sup>. These comparatively high levels of HIV have, over the course of the epidemic, been the subject of much epidemiological, media and individual scrutiny.

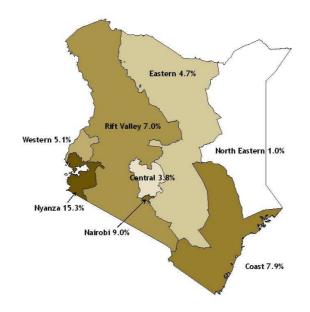


Figure 9. HIV prevalence in Kenya by province, Kenya AIDS Incidence Survey 2007 (NASCOP)

Epidemiological prevalence mapping follows the political/geographical divisions which have become hegemonic in Kenya and which overlay geographical boundaries with ethnic ones (see pp. 32-4). Therefore, to speak of high prevalence in Nyanza province becomes more or less equivalent to speaking of high prevalence among Luo people, who form the majority ethnic group in the province.

As elsewhere in Africa, explanations for HIV prevalence in Western Kenya often isolate particular "cultural practices" as responsible for the spread of HIV/AIDS and as an impediment to prevention work (Gausset 2001). During the 1980's and 1990's, the escalating HIV/AIDS epidemic in Africa and the realisation that much greater numbers of African women were becoming infected than in Western Europe and North America prompted a new tranche of studies on "African sexuality" (e.g.

<sup>&</sup>lt;sup>34</sup> Given the different methods of data collection, and that earlier estimates of prevalence have since been revised downwards, it is perhaps not possible to directly compare these figures. However, the fact remains that this district is well-known to have a much higher than average incidence of HIV.

Caldwell et al. 1989). Some spoke of the ensuing 'invention' of African AIDS (Patton 1990), a discourse which broadly speaking made links between the particular path that the epidemic seemed to be following in sub-Saharan Africa with what were thought to be broadly shared patterns of 'African sexuality' across the region, in ways which often drew upon longstanding prejudices and racist notions of 'African promiscuity'.

As Gausset (2001: 510) has pointed out, the kinds of cultural practices which have been seen as problematic in the context of the HIV/AIDS epidemic are often those same aspects of African sexuality which were identified as irrational or immoral in early studies of African sexuality. These studies were obsessed with 'exotic' difference; the most different kind of difference from a 'Western' perspective: polygyny, widow inheritance, clitoridectomy, and so on. Like the older studies referred to by Gausset, more recent studies of African sexuality have generally focused on these 'exotic' practices whilst simultaneously ignoring other kinds of difference around sex and sexuality, including restrictions and limitations placed around coitus and other expressions of sexuality in a variety of African contexts (Heald 1995)<sup>35</sup>.

To think about HIV/AIDS as a complex discursive construction is not to engage in a search for hidden 'truths' about the epidemic, but rather "to sort out how particular versions of truth are produced and sustained, and what cultural work they do in given contexts" (Treichler 1989: 48). It is thus to draw attention to the topographies of power which give credence to particular kinds of representation of HIV/AIDS as a disease as well as of those infected and assumed to be at risk.

The task of unpacking the discursive complexities of AIDS has constituted a significant and important contribution of anthropologists and other social scientists towards understanding the effects of the epidemic. For example, anthropologists have led the way towards understanding how "geographies of blame" (Farmer 1992) intersect with the lived experience of the epidemic, and have attempted to contextualise enduring controversies such as the South African response to HIV/AIDS under Mbeki (Fassin 2007). More generally, analyses carried out by anthropologists and other social scientists have underlined the racist undertones of some medical discourses about AIDS (Patton 1990: 77-97, Schoepf 2001, Seidel 1993), have criticised the related focus on so-called "high-risk groups" rather than the realities of managing everyday life which have exposed people, especially women, to HIV (Schoepf 1997, Wallman 1996), and shown how responses to AIDS within the fields of medical research have been shaped by longstanding stereotypes of African behaviour (particularly

<sup>&</sup>lt;sup>35</sup> For a notable exception, see Tony Simpson's (2009) insightful account of sexuality and masculinity in Zambia.

assumptions about promiscuity) ,to the exclusion of wider epidemiological issues (Packard and Epstein 1991).

In Kagot during the period of the fieldwork upon which this thesis is based, many different kinds of discourse about why Luo communities were so severely affected by HIV/AIDS existed simultaneously. To describe this discursive complexity in detail could be the topic of a whole thesis in itself if one wished to properly account for shifting meanings of the disease across different contexts and the varying terms within which HIV/AIDS was discussed. HIV/AIDS was at times highly stigmatised yet at others engaged with as "just the disease going around" – sometimes by the same people in quite quick succession (pg 95). Others blamed the rise of the disease on a rejection of the 'old ways' and a failure to properly follow certain 'traditional' rules (*chike*). HIV/AIDS has become situated in a relationship with *chira*, a wasting disease understood to be the result of breaking taboos (*kweche* sing. *kwer*) or the failure to follow rules of hierarchy such as when planting crops or building houses. The relationship between *chira* and HIV/AIDS is complex, with some suggesting the diseases are completely different. For these people, ARVs are ineffectual in the treatment of *chira*, which could only be cured by ritual specialists and Luo medicine (*manyasi*). For others the diseases overlapped.

For those practicing HIV prevention and care, 'belief' in *chira* was often seen as a "cultural impediment" to dealing with HIV/AIDS (Owino 1998). Issues around *chira*, HIV/AIDS and the following of traditional rules have become the subject of intense debate among Luo people themselves. Many are concerned with the wider moral connotations of social disorder resulting from (and to some minds causing) the death of so many (cf. Prince 2007). Meanwhile, information about HIV/AIDS (along with many of the debates growing up around it) has been represented through many different forms of print, visual and aural media, in three different languages. The interventions of national and international health agencies and of religious groups continue to take large areas of the discursive nexus, with these groups themselves hugely diverse, including very small independent Luo churches with only a few members, as well as transnational Pentecostal churches.

I will briefly consider three significant points at which many of the discourses about high prevalence converge which I feel are particularly important to understanding the context of HIV/AIDS in this region and the debates around why HIV prevalence is so high here. The three issues, understood most frequently as 'cultural problems' complicit in the spread of AIDS – although of course not all see them as such – are male circumcision (or the lack of it), polygyny (or 'concurrent partnerships') and so-called 'widow inheritance'. The discursive convergence around these three issues with 'Luo

culture' has two significant effects; firstly it establishes aspects of 'Luo culture' as problematic, building upon a discursive history dating from the colonial encounter in which 'culture' and 'tradition' were aligned to a lack of education/enlightenment and general 'backwardness' (Ogot 1963: 256). Secondly, they create a homogeneous sense of Luo culture, where Luo people's risk of HIV is assumed to be determined more by the way that Luo people are different from other ethnic groups than by different kinds of behaviour between Luo people, or by wider structural problems of politics and economy.

Firstly, circumcision: A large number of clinical trials have been undertaken in Kisumu in recent years, many relating to HIV and AIDS. These have included the now famous study on male circumcision which concluded, "Male circumcision significantly reduces the risk of HIV acquisition in young men in Africa" (Bailey et.al. 2007). While health agencies and epidemiologists have been thinking through how best to promote male circumcision, and whether it can be carried out safely in resource-poor areas like Western Kenya (Bailey et al. 2008), male circumcision as a HIV reduction strategy remains controversial for many<sup>36</sup>, not least because male circumcision is not 100% effective in protecting against HIV/AIDS, and whilst it reduces the risk of HIV infection to men, it does so only "indirectly" to women, and perhaps even increases women's risk (e.g. Machirori 2009). Meanwhile, it is also clear that low circumcision rates do not universally correspond to high levels of HIV, and that reductions in HIV prevalence are possible without increasing rates of circumcision (Moore and Hogg 2004: 546).

These complex and often heated debates fall largely outside the scope of this thesis. The lack of circumcision among Luo men was very much on the agenda as a reason for high prevalence during the fieldwork period and the clinical trial cited above was completed during the fieldwork period. However, it is in the period since fieldwork was completed that the most vigorous debates on male circumcision in this region have taken place (e.g. BBC News 18th July 2008). However, from a discursive perspective, one interesting thing about debates around circumcision is that by bringing together 'Luo culture' and a 'failure' to circumcise as problematic, they converge with longstanding inter-ethnic discourses of cultural difference in Kenya, where the majority of ethnic groups practice male circumcision. This is particularly true of the relationship between the Luo and Kikuyu peoples (e.g. Atieno-Odhiambo 2002: 240-5)<sup>37</sup>. Circumcision has been an issue during all the election

<sup>&</sup>lt;sup>36</sup> For example see the discussion between (Green et al. 2008) and the rejoinder: (Halperin et al. 2008)

<sup>&</sup>lt;sup>37</sup> The distinction developed around both male and female circumcision. See (Kanogo 2005).

campaigns that have taken place since multi-party politics was reintroduced to Kenya in 2001<sup>38</sup>, with many non Luo people (including high level politicians) raising questions about Luo politicians' fitness to lead Kenya given the fact that they do not practice male circumcision, for example describing them as '*kihii*', the Kikuyu term for uncircumcised boys.

More recently, circumcision became a focus for violent ethnic difference during the post-election violence in 2008 which took place after fieldwork for this project was completed, when there were reports of Kikuyu youths forcibly circumcising Luo men (Nairobi Chronicle 7th October 2008). The Luo council of elders, who are often called to speak for the Luo community on matters of 'culture' (e.g. Carotenuto 2006), initially rejected plans to introduce circumcision as part of an HIV prevention, arguing that circumcision is "against the community's culture", although they have more recently began to make concessions on this issue, it remains a matter of controversy and debate. The alignment of health and 'culture' in the new discourse on circumcision is problematic in the context of these wider debates about ethnicity in Kenya.

Widow inheritance and polygyny can be discussed together. As I mentioned above, both polygyny and widow inheritance, called *tero* in Luo, which literally means to take, but which is referred to as 'widow inheritance' by English speakers, were the subject of missionary disapproval and deprecation from the colonial period (Kirwen 1987, Ogot 1963: 256, Strayer 1978: 79-81). Among Luo people, as among the neighbouring Maragoli (Mutongi 2007: 112-4), the rejection of polygyny was for some a sign of a progressive man in colonial times. However, polygyny remained widely practiced among Luo people throughout the colonial era and after independence. During the 1970's David Parkin (1978) noted that Luo men's increased migration to Nairobi for wage labour was in part managed by polygynous marriages which allowed Luo men to simultaneously manage their urban and rural concerns by having a wife in each location. Parkin argued not that under the growing influence of the labour market polygyny shifted slightly in terms of meaning and function, and remained practically useful whilst simultaneously drawing upon ideological values considered as traditional, particularly the importance of creating large families with many children. In Chapter 7 I suggest that polygnyous families are also a valued resource against the background of managing responsibilities of care in the context of HIV/AIDS.

<sup>&</sup>lt;sup>38</sup> Except the 2002 election where the most prominent Luo politicians supported Kibaki in a broad coalition that came together to fight the incumbent KANU party.

Despite shifting practices of polygyny under the experience of capitalist modernity, and partly as a result of these changes, polygyny has remained associated with the 'traditional'. As in the case of male circumcision, polygyny also became a marker of inter-ethnic difference between Luo and Kikuyu who had in general embraced monogamy more wholeheartedly than the Luo following missionary conversion. Parkin argued that the opposition between polygyny and monogamy for the Luo was part of a broader discussion ongoing between Luo people during the 1960's about the potential benefits of individual success versus the advantages and disadvantages of adhering to collective Luo customs, "The generalized opposition between Luo and Kikuyu is really another way of talking about the opposition among Luo themselves concerning polygyny versus monogamy and the old and new cultural paradigms represented by these two systems of marriage and family" (Ibid.: 295).

In light of the apparent success of HIV/AIDS prevention campaigns in Uganda which promoted 'zerograzing' (a reference to an agricultural practice where cows are tethered rather than herded, taken to mean one should stick to one partner/keep sex at home), recent socio-epidemiological studies (Epstein 2007, Thornton 2008), have again put the spotlight upon polygyny and other sexual practices assumed to open up networks of "concurrent partnerships".

This perspective does not necessarily view polygyny or indeed other kinds of sexual relationships as problematic. For example Thornton writes, "HIV is an infection of sexual networks...whether sex takes place in marriage or outside of it is less important than the sexual links that are formed" (2008: 229). Thornton sees himself as promoting a method of AIDS prevention which moves away from moralising and largely ineffective abstinence discourses (Ibid.: 220-234). Meanwhile, Epstein (2007: 196) argues that the zero-grazing campaign was successful in Uganda because it told people to keep sex at home, but did not moralise about what kind of sexual relations one should have there (Ibid.: 195-6). Nevertheless, polygyny is seen to create 'clusters' of sexual networks which are assumed to be easily opened to the HIV virus as men or women take up relationships outside of marriage (Epstein 2007: 55, 69-71, Thornton 2008: 65-6). My point is that such discussions are all too easily conflated with a discourse of 'cultural impediments', where the blame becomes placed on a particular cultural practice (polygyny) rather than on the specific kinds of risk situations in which people in polygynous unions find themselves.

However, of all these practices, it is widow inheritance which has been the subject of the most widespread recrimination and debate both between and about Luo people (Agot 2005, Dilger 2006, Prince 2007). Widow inheritance involves the ritual sharing of food with an inheritor and the sexual

cleansing of a widow some time after the death of her husband in order to 'open' the way for her children's future prosperity. It often results in a long term relationship between the widow and her inheritor (*jater*). Inheritance can be carried out either by a classificatory brother-in-law or a professional inheritor, and for some Luo people it is the growing commercialisation of this ritual, rather than inheritance *per se* which is problematic (Luke 2002, Prince 2007: 87)<sup>39</sup>. For others, in particular those who have been 'Saved' and consider themselves to be 'born-again Christians', inheritance is viewed as heathen backwardness and is a traditional practice which is incompatible with modern Christianity (Prince 2007). Susan, one of my young informants explained it like this:

"Some young women, they just do it [inheritance] because they want to have another life. But if you have a son and he wants to build a house you have to be inherited, also if you want to re-do your own house. Unless if you are strong in church you can get help to build a new house but if you are not Saved you cannot just adopt those cultures because nobody will help you. If you are not Saved if you are just a normal Christian then you have to do them. So in Kenya unless you are Saved is when you can be free" (Fieldnotes 19<sup>th</sup> October 2006).

More broadly, and in ways which echo the discourses of Saved Christians who emphasise widow inheritance as 'traditional' and belonging in the past (cf. Prince 2007: 86), the practice of widow inheritance is discussed in a wide range of media in ways which position Luo people as both geographically and temporally other (Agot 2005, cf. Fabian 1983). In these texts, widow inheritance is seen as an outdated, backward practice (rather than a rational response to bereavement) to be solved by increased education which will lead to the eventual rejection of such practices. Such representations can be found in a variety of different media. An article in the Washington Post describes widows in "places like Busia" (a town on the Kenya Uganda border) who undertake inheritance as women who "possess little education" (November 8th 1997). The Kenyan government has suggested that widow inheritance be "eliminated" (Agot 2005: 365, Luke 2002: 1), and some of my own informants made statements like "widow inheritance should be abandoned!" Such statements form a counterpoint to the viewpoint held by many other Luo people that high levels of

<sup>&</sup>lt;sup>39</sup> The separation between cleansing (*golo chola*) and inheritance (*tero*) is longstanding. For example Evans Pritchard (1965: 242) wrote, "It is customary to get a...person outside the clan, to sleep with the widow before the brother does so, in cased the husband's ghost is troublesome." See also (Ayikukwei et al. 2008). However, there is a sense among many in Kagot that the rise in the number of widows and a growing reluctance by in-laws to perform the ceremony has led to the increased commercialisation of the ritual in recent years.

disease are the result of a *failure* to follow practices such as widow inheritance (Agot 2005: 365-70, Dilger 2006: 114-5, Prince 2007: 86-8).

Widows often find themselves under pressure from their extended family to undergo inheritance, as refusal to carry out inheritance is understood by many to put the whole lineage at risk of death and stagnation. Other women are keen to be inherited, as inheritance means that women's sons can leave home and set up their own homes and that widows themselves can build or repair their own houses. It also allows women to carry out a range of activities which require ritual sexual activity, usually in order of hierarchy within the family, such as at the commencement of planting season and following periods of mourning. Others find companionship and sexual satisfaction in their new relationships. Moreover, once inherited, a woman can continue to bear children in the name of her late husband.

Widow inheritance is sometimes idealised as a support mechanism for widows. Ocholla-Ayayo (1976: 144) translates *Jater* not as inheritor, but as 'care taker'. Others agree with Judith, who saw it the other way round. She thought that being inherited would increase the burden of care upon her;

Hannah: Do you think you will ever get another husband?

**Judith**: No I don't want one. Imagine I am fine. I just want to be with my children and care for them. Those men who take a woman who has already been married they just do it because they want things. They come and expect food and warm water for bathing, they can't bathe in cold water, and they wear the clothes of your dead husband - they take them all, all of them! He will ask for tea but he will not drink that black tea, only the one with milk. You can go to town and come back and find that man has beaten your children, because he won't like them because they are not his.

This discursive complexity can be understood as contextual. I have introduced these issues in an effort to situate care (as a set of responses to HIV/AIDS) within a much broader set of cultural processes which are both a set of responses to HIV/AIDS, but are also practices which dynamically construct and change illness. These processes influence the way HIV/AIDS is thought about and experienced by aligning affliction with a complex set of moralised constructions of 'cultural' difference.

An issue which cuts through all of these debates which has received relatively large amounts of attention in research on the HIV/AIDS epidemic, is the way in which the epidemic and risk of illness is

gendered, with disproportionate numbers of infections among women underlining broader gender inequalities (e.g. Baylies 2000, Baylies and Bujra 2000a, Bujra 2000, Obbo 1995, Schoepf 2001). In a pattern similar to other African sites, a 2003-4 study conducted in an area overlapping part of Kagot District showed that women aged 13-34 years were almost twice as likely to be infected with HIV as men of the same age (Adazu et al. 2005: 1152). Women are not only more likely to be infected from HIV/AIDS, but are also more likely to assume caring responsibilities for the sick (Akintola 2006, 2008, Chimwaza and Watkins 2004, Nnko et al. 2000: 797, Ogden et al. 2006). The gendered nature of care work in Kagot is a central theme of this thesis. However, I attempt to move beyond analyses which focus primarily on care-work as women's burden, to think more broadly about the ways in which caring practices shape gendered identities in ways which both empower and restrict women as they manage lives lived in the shadow of AIDS.

In the next sections of this chapter I continue the task of contextualising this thesis with a discussion of the three key terms of the thesis; care, home and hospital.

#### Defining care

There is no single analogous term in Luo which covers the breadth of emotions and practices that I call care. However, my definition of care encompasses a wide range of practices which are of central importance to Luo people. Some of the many Luo terms which I gloss under the umbrella of care include *hero* (v) love, like, favour, admire; *rito* (vt.), wait, watch, take care of, guard; *rango*, (vt.) look for, search for, wait for, care for, await; *pidho* (vt.), rear, bring up, nurse [a child], nurture, breed cattle, plant seeds; *konyo* (vt.) help, assist, aid, support (Bole Odaga 2005).

One thing which is interesting about these Luo terms *vis-à-vis* their English translations, is that the English terms can be relatively easily divided into those pertaining to emotion (thought of as interior to the body) and others pertaining to practice (external to the body); a Cartesian type dualism based upon a way of understanding the body, the person and the way people act upon the world which assumes the existence of an interior self with internalised feelings which are understood to influence action (cf. Rose 1999 [1989]). The pervasive nature of this dualism is signified by its prominence within the many studies on care which reflect upon the relationship between care as labour (caring for) and care as emotion (caring about) (e.g. Finch and Groves 1983, Kittay 1999, Read 2007, Tronto 1993: 105-8). However, Luo people I came to know during fieldwork did not make this kind of

distinction between emotional feeling and emotional action. For many of my informants, emotion and action necessarily went together.

Anthropologists have long argued against the universality of emotional meaning and expression; suggesting that emotion differs cross culturally (e.g. Briggs 1970, Lutz 1988). So it should not come as a surprise that Luo people do not distinguish between emotion and action in the same way that is prominent in Western thought. As in some other African settings, many Luo people understand emotions as agentive. In this sense, emotion/practice is less about the relationship between an interior self and the practices presented to an outside world, and more about a person's relationships with other people and the *effect* that emotion/practice can have on them. For example, in a (2002) article, Durham and Klaits argue that in Botswana, funerals are an important site for the management of what they term the "social effect of sentiment";

"In Botswana...what we refer to as sentimental dispositions - sorrow, caring for one another, love, jealousy, anger, resignation - are seen to possess a crucial influence over the bodily, emotional and material well-being of *other* people. Because the mutuality effected through sentiment can be both extremely beneficial and extremely dangerous, mutuality is a highly ambiguous phenomenon, and sentiments must be carefully managed" (Ibid.: 779, emphasis added).

Elsewhere, Klaits writes in more detail about the sentiments of love and care in an urban Batswana community, and emphasises the relationality of sentiment. He argues, "Emotion is not understood as distinct from action, or vice versa" (2002: 7). As in Botswana, the time I spent in Kagot alerted me to the fact that for the Luo people among whom I carried out fieldwork, it was essential that emotions (and emotional practice) be managed properly because of the agentive potential that emotions had outside of the individual's body. For example, among adults, weeping was considered highly inappropriate except at a time of bereavement, even at times of great distress;

**Susan**, one of the young women who worked in the organisation I describe later in the thesis, told me proudly that **Elizabeth**, her boss, had "chased away" a mother who arrived at her dying daughter's bedside in hospital because of the way she was crying. The young girl had been bitten by a rabid dog and was now dying of rabies; a drawn-out and painful death<sup>40</sup>. The mother had not seen her daughter for some four years prior to this event because, as is quite common practice, she had sent her daughter to live with maternal

<sup>&</sup>lt;sup>40</sup> She had been bitten some time ago and not received treatment before symptoms appeared. Once this happens, there is no treatment and death is inevitable.

relatives and had not managed to visit her. I objected to **Susan** that the woman must feel terrible to know her daughter was dying (especially after not seeing her for so long) and perhaps in such circumstances it was understandable that she was crying.

**Susan**: The mother came in while we were [at the hospital] and saw her daughter and started crying and the girl start crying as well and Elizabeth chased her away. Elizabeth was telling her to cry afterwards [later, away from her daughter] because she was disturbing the girl.

Hannah: But is crying really so bad, surely it's just part of life?

**Susan**: But we Africans do not cry unless maybe someone has died, but if someone cries we are scared.

Crying scares people because of its close association with death. While at other times crying is taboo, during the mourning process crying is essential. Around Kagot it is the sound of a high-pitched woman's wail that is often the first notification that a death has occurred. However, it is not simply that crying reminds people of death, but more broadly that the excess of sorrow which is the result of being close to death can be transferred to others and therefore can also bring death closer<sup>41</sup>, crying out of place, therefore, gives the sense of someone reaching out towards death, and of death's contagion.

Just as weeping had a potential agency so did words. Some of my informants told me that those who practised witchcraft employed certain objects and medicines for their occult ends, describing how they had discovered medicines, or suspicious out-of-place objects. However, it was also clear that words alone could sometimes be enough of a vehicle for witchcraft, and jealous, angry statements were sometimes understood as the cause of a particular misfortune. Witchcraft could be done in the talking of it; Beatrice blamed the death of her friend in a road accident on the strange greeting offered to her by a third woman shortly before she departed on her journey home. Meanwhile, although people sometimes told of accusations of witchcraft and the jealous sentiments harboured by those who wished them harm, they would not go into detail about *how* they thought the witchcraft might have been done. To do so would not simply align them with those who *knew* about witchcraft, but could also provide a vehicle for witchcraft to literally come back to haunt them.

<sup>&</sup>lt;sup>41</sup> Comparably, Janice Boddy, writing about the Zār cult in Sudan describes how it is often emotional distress in the human world which causes spirit illness (Boddy 1989: 137; 240; 252)

The emotion most closely related to witchcraft was what Luo people termed jealousy (*nyiego*)<sup>42</sup>. In Kagot people told me that jealousy could cause harm, either deliberately or accidentally, without the knowledge of the individual harbouring the emotion. Luo people recognise that jealousy has a place in normal everyday life; indeed Luo the term for co-wife, *nyiego* is also the term for jealousy. Co-wives refer to one another as *nyieka*, my partner in jealousy. The fissures of jealousy that occur between co-wives in Luo households and the half-brothers whom they mother are understood structurally as the points where new lineages can become created, and indeed as the origin of the lineage structure (Southall 1952). What is important about jealousy is that because it is accepted as a normal part of daily life *and* as an agentive emotion which can have an effect upon others, it must be managed properly. It is for this reason for example, that the special hut known as *abila*<sup>43</sup> which Luo families sometimes build as a place where a man can attend to his personal business, especially when he is old, is traditionally located out of ear-shot of his bickering wives, thus protecting him from the agentive qualities of their jealousy (Southall 1952: 16).

Like jealousy, love (*hera*) and the range of terms above which I gloss as care, are agentive emotions in the dual sense that they have an effect on others and that they are considered to consist equally and inseparably of feeling and activity. During a long interview, Judith, who was HIV+ and very weak, spoke to me about how she was coping with her illness. She told me of her admission to hospital after she had developed a problem with her hand, and she described how her friend Awuor helped her;

"I just lose hope with this illness. I just lose hope. But just by the help of my friend Awuor I am doing OK. She used to visit me. *Aki* [Oh!] she gave me all the love. You would think she was my sister. She used to visit me. She washed my children, she washed me. She shaved my hair. Mmm, *s*he loved me. Them, they are rich, they are well off. She used her money, mmm. When my hand was feeling different, she took me to the hospital with *bodaboda* [bicycle taxi]. She just came here with a *bodaboda* and took me to the hospital. I think I stayed there for three weeks, almost a month. She also had a sister in that hospital. I

<sup>&</sup>lt;sup>42</sup> The term jealousy as used in Kagot encompassed both envy and jealousy. The relationship between witchcraft and jealousy has been widely noted across a range of African sites and I do not have space to consider this literature in full. Some examples include: (Ashforth 2000, 2005, Beattie et al. 1963, Durham 2002, Durham and Klaits 2002: 784)

<sup>&</sup>lt;sup>43</sup> One of my informants, Beatrice translated *abila* as a man's "office", a translation which I found useful because *abila* are used for men to hold meetings and attend to their business. *Abila* also has a number of other meanings and uses (See Bole Odaga 2005: 15)

came back here. She has given me much love, until I just...I feel safe. And also the type of parents<sup>44</sup> I have....I really find them loving".

Notice that while Judith describes Awuor's love through a relational idiom, she also describes the kinds of practices that love consists of via a complex mixture of Awuor's actions and sentiments, so that visiting, helping with her children, giving financial support, physical hands on care and emotion are blurred together. They are love (cf. Durham 2002). But what is important is not just that actions of emotion cannot be distinguished from feelings of emotion, but also that this emotion has agentive potential, for example to aid recovery.

It is with this active sense of the term love in mind that one can understand another informant's description of the structural weakness that women find themselves in when they marry and move into their husband's family. "The problem for Luo women is that their in-laws don't love them," Elizabeth told me, signalling that it is a lack of love in both its emotional and material aspects that holds back women's individual progress. Similarly, a story which Beatrice loved to repeat centred on the circumstances of her first marriage. She described how as a young woman, her first husband had tricked her into leaving school with two years of secondary education remaining, offering her the empty promise to finish her secondary career at her new home in exchange for marrying him. The deception was exacerbated in her laments, because the Norwegian missionaries who ran the school she attended, as she put it, "really loved me!" Their love would have guaranteed the exam success and subsequent employment of which she was cruelly cheated.

It would be true to say that I was inspired to think about care as practice by reading books, far away from Kagot town and Ramira village, no doubt influenced by contemporary fashions in anthropology. However, coming to learn from Luo people about care as an agentive emotion made thinking about care as practice appealing *because of* my data. One of the reasons why I have found this theoretical framework interesting and useful is because of the way that it converges with the kinds of theories that my informants in Kagot and Ramira had about care and other agentive emotions like love and jealousy. It seems to me that in a context where emotions are agentive and care is understood as agentive emotional practice, but not separable into these constitutive parts, that following practices of care and understanding how love, support and help are *done* also makes sense from an emic perspective.

<sup>&</sup>lt;sup>44</sup> Here she is referring to her husband's father and mother.

#### Ноте

The first thing that any Luo person will tell you about home, is that a house (*ot*) and home (*dala*) are not the same thing. A house can be anywhere, perhaps a rental room in Kisumu or Nairobi, but home refers only to one place, the 'ancestral home' and the place where one will be buried. Home is a plot of land, usually rural or semi-rural, generally consisting of a number of houses within a marked boundary. The men who start these homes, usually by moving onto a plot of land adjoining their father's homestead, but sometimes by purchasing a piece of land, are referred to as the owner of the home; *wuon dala*. Houses are built within the home for each of a man's wives, and as their sons grow older and approach marriageable age, they too build houses within the home, which are known as *simba*. Often, younger men's wives come to live with them in these houses for many years before they can afford to leave and set up their own homes. Setting up a home is an important development for a Luo man, and he will be referred to respectfully as a man of a certain place (e.g. *JaKagot*) rather than a son (*wuod Kagot*) once he has done so (cf. Cohen and Atieno Odhiambo 1992).

Luo people share an understanding that there exist an extensive set of more-or-less strict rules about where and when houses can be built within homes. This is not to say that such practices are static, on the contrary, but rather that certain general principles exist which are broadly shared across different sections of the community<sup>45</sup>, within which some aspects are the subject of discussion, debate and change<sup>46</sup>. Certain key principles of house building are followed in ways which are similar enough to generate a shared sense of how things are and should be done across the Luo community.

These principles mean that homesteads become openly recognisable as physical and symbolic maps of familial relationships. The first wife's house, for example, is always located directly opposite the front gate and usually on higher ground, so that water and dirt wash out of the home; 'up' carrying associations of health, prosperity and seniority. The first wife's seniority is thus represented in the

<sup>&</sup>lt;sup>45</sup> I observed these building patterns in every home that I visited during fieldwork, including the homes of wealthy Luo business men who lived mostly in Kisumu or Nairobi, those of families who considered themselves Saved Christians as well as those of small-scale farmers, teachers and nurses. Only rental properties and business premises were not built in this way. However, even rental properties were also frequently built broadly in the same style, with a larger house looking down over two rows of smaller rooms facing into the plot. Given that the layout of the houses did not have any relational symbolism I took his building style as suggestive of a broader aesthetic appeal that grew out of the way houses were arranged in homesteads.

<sup>&</sup>lt;sup>46</sup> For example, some wealthy people spend a lot of money on their homes and wish them to be used again by their children, such houses are sometimes symbolically rebuilt by changing the location of the door and moving the gate to the home. Other people avoid rebuilding their whole house, for example in line with the tradition that the first house built in a home must be built in a day and that a larger house is built later in the cycle of the home, by simply replacing a few sheets of corrugated iron on the roof of the house.

location of her house, and frequently also in its size, as in polygynous homes the houses of second and third wives (built to the left and right of the first wife's house respectively, from the point of view of the gate) are frequently smaller than the first wife's house. Sons' houses, built lower down in the compound, are always smaller. Sons build their houses in birth order beginning to the left of the first wife's house as one looks at it, but facing the centre of the home rather than the gate as in the case of the wives' houses. Sons build on alternate sides of the compound gradually getting nearer to the gate (cf. Ocholla-Ayayo 1976: 144, Southall 1952: 16-7)<sup>47</sup>. This is an ongoing process, with houses and house-building embodying the generational flow of familial relationalities over time (Prince 2004: 141-68).

Visitors can thus learn something of the people who live in a particular home just by looking at the location of the houses; how many wives a man has, for example, and how many grown sons. Houses are also indicative of wealth, both in terms of size and the way that they are built. The most notable markers of prosperity are corrugated iron roofs and concrete floors, but there are others, such as guttering and large water collection butts, and for a very wealthy few, solar panels and even mains electricity if one lives in town or near the road.

But houses can also be read in other ways; if a house is closed up, this is often because its owner lives and works away, and migration is a mixed blessing, potentially a sign of individual success and access to the wealth of wage labour, but also of the absence of a family member. A crumbling house is almost never a favourable indicator; it can be a sign of poverty or illness, perhaps the owner is too weak or poor to repair it, or cannot garner the support of others<sup>48</sup> to make the mixture of mud, ashes and cow dung which must be smeared periodically on the walls to prevent them from decaying. Or it could be that the owner is dead, as houses are almost always built only for specific people<sup>49</sup> and once that person dies their house cannot be used by another.

The traditional way of building homes was in a large circle, but now one frequently finds homes built on rectangular plots with the son's houses built in straight lines at right angles to the wives' houses. Perhaps this is a result of the missionary obsession with *illini* (lines), see (Mutongi 2007). It is also very rare nowadays to find round huts.

<sup>&</sup>lt;sup>48</sup> As far as I witnessed, smearing mud was only done by women.

<sup>&</sup>lt;sup>49</sup> The exception is the *simba* which acts as a dormitory for all young sons in a family until the eldest son marries and takes it over with his wife. Less often, wealthy families sometimes build a dormitory for older girls to sleep in. Neither girls nor boys can sleep in their mother's houses once they reach an age nearing puberty so this is a practical option if there is no other place nearby (for example a grandmother's house or a kitchen) where these young people can sleep.

In Ramira village, as in other rural parts of Kagot district, in some places long grass has grown over whole plots and all the houses within them have completely disintegrated. In such cases, empty homesteads have become silent memorials to the many people who once lived in them, marking the recent ravages of death through their absence.

### Home, growth and prosperity

Writing about house building leads back into the discussion I began earlier on widow inheritance. For many of the widows I met in Kagot and Ramira, it was particularly the difficulties which they encountered around house building and house repair which brought the issue of widow inheritance into sharpest focus.

One day, I visited Judith and found her resting in her own house with her young daughter. On previous visits to her home I had always been with a Community Health Worker who was a friend and fellow church member of Judith's father and mother-in-law. We always called at the first wife's house, the largest of the compound and full of many chairs to receive visitors. However, on this occasion I visited alone and the main house was closed up when I arrived. Judith invited me into her own house. I knew already from our discussions that Judith's house had fallen into disrepair since the death of her husband. However, seeing and feeling for myself the dampness in the air, the crumbling walls and floor, and the seeing the loose grass roof which surely allowed rainwater to leak water all over her bed (the only item of furniture in the room), gave me an added sense of the difficulties that she was facing. We talked a little before Judith's mother-in law arrived home and called us up to her house to greet her. Once there, we took tea and I asked Judith, "Is there not anywhere else you can sleep?" thinking that someone so ill should be sleeping somewhere warmer and drier. She replied,

"I can't sleep here [in my mother-in-law's large house], it's a taboo. Even my children can't sleep here because their father-in-law is still alive<sup>50</sup>. If we didn't have traditions life could be easy, I could just sleep here...my father-in-law is not allowed to help me repair that house, there are so many taboos."

Christine's situation was similar. Like Judith she was in her late 20's, although her living conditions were worse. She was living in a tiny single-roomed dwelling that was literally falling down around

<sup>&</sup>lt;sup>50</sup> Children can only sleep in their grandmother's house once she stops being sexually active. The sexuality of adults is thought to present a risk to children.

her. However, unlike Judith, Christine desired inheritance, seeing it as the answer to her troubles, but she was so visibly ill that none of her in-laws was willing.

Over December 2006 the short rains had been unexpectedly heavy and Christine's house had only just escaped the torrents of rain that had fallen. The tops of the walls of the house had completely washed away and there were big gaps between the walls and the roof, where the wooden poles which formed the framework for the mud walls were becoming visible. Christine had pinned thick plastic sacks to the walls to cover up these gaps in an attempt to keep rain and draught from entering. The room was dreadfully damp and Christine told me of her terror at waking up in the middle of the night to find water had reached half way up the leg of her bed. It was clear that she could not stay in the house for much longer, and she explained that she wanted to find a house to rent.

Hannah:Now you don't want anything to do with inheritance?Christine:I don't want it right now. But renting is not bad [i.e. it is not in breach oftraditional rules].But building your own home, you can't do that.Hannah:Can't you sleep in your mother-in-law's house?Christine:I can't. The children can sleep there but I can't... The other day it reached9pm and it was raining so much.My mother-in-law said, "Stay and sleep here" but Irefused, I said, "People will talk badly of it<sup>51</sup>, people will say that I asked you to do this."

Christine's terrible living conditions had come to the attention of the NGO, Mildmay who supported the Community-Based Organisation I describe later in the thesis. Christine and her mother-in-law, Rose, were the only adults living in their home and Christine, who was thin, weak and had developed chronic arthritis, was hardly well enough to care for herself. Somehow through a small business selling samosas, Rose supported Christine and her four children along with eight other orphaned children in the home, including a young baby who was HIV+ and chronically sick. Rose and Christine were frequently introduced to visitors to Kagot Development Group, partly because of the particularly desperate situation in which they were living, but also because their home was conveniently located on the periphery of Kagot town, just a short walk from the organisational office.

After one particular visit, Mildmay officials offered to supply funds for the repair of Christine's house. However, this was problematic. Elizabeth explained the matter thus: Christine's mother-in-law (who was not ethnically Luo, but a Luhya from nearby Western province) was concerned that the boys in

<sup>&</sup>lt;sup>51</sup> Swa. *wataleta maneno mingi*, literally, "they will bring lots of stories".

the family were going to grow up and get married and there was no more room in their plot to build more houses. She had purchased a small plot of land further out of town and wanted Christine to build a house there. However, Elizabeth went on,

"The problem is that because there is no husband they can't build a house because they need a husband to put the door. The grandmother wants her to build a house but she's saying that no-one can put the door because the husband has to do this. I have just left them to discuss it together, they are the elders of this family and they are having 12 orphans. Let them come together and reach a decision. But the problem is, that woman [**Christine**] is really fearing. She's really fearing because she's been going around and people have been telling her, "No, [you cannot build a house] because there is no husband", and she is also not fully participating in church. That woman sees *tero* [inheritance] as the answer, but Mildmay cannot support inheritance."

Home, family, growth and prosperity are intimately connected for Luo people (cf. Prince 2004), with houses physically standing for people and their relationships to others. Houses also organise relationships by allowing people to sleep in the proper place and thus to generate new relationships without the problematic mixing of the sexuality of different generations (cf. Geissler and Prince 2004). Houses symbolise and are built in ways which emphasise a gendered division of labour and the roles and responsibilities of men and women in the future growth of the home and by extension the lineage. This understanding of growth ties increment, prosperity and improvement together and is denoted in the Luo verb *medo*, meaning to add, multiply and increase and its related noun, *medruok*, meaning betterment, improvement, multiplication (Bole Odaga 2005).

The opposite of growth is sterility, death and atrophy and is, for many Luo people, epitomised by the illness *chira*. *Chira* is an illness of decay, sterility and blockage symbolised by the literal decay and wasting of the body (Abe 1981, Ocholla-Ayayo 1976: 104-4; 146-50, Parkin 1978, Prince 2007: 86-8)<sup>52</sup>.

<sup>&</sup>lt;sup>52</sup> *Chira* is often described as being an illness caused by breaking 'traditional' prohibitions (*kweche*). However, Ruth Prince (2007: 100-2) argues that *chira* has increasingly become relevant as a 'Luo illness' only in relatively recent times, with both *chira* and the existence of 'traditional rules' (*chike*) increasingly codified as 'traditional' and as central to 'Luo custom' over the recent historical period, with the first mentions *chike* as a list of fixed rules central to Luo culture in the 1970's. Prince argues that this is partly as a result of a missionary encounter which posited a 'traditional' realm as one opposed to the practices of modern Christianity, but also to shifting meanings of ethnicity within the wider context of increased urbanisation, wage labour and migration.

The illness *chira* is as matter of intense debate among Luo people and *chira* is a highly contested concept. Some Luo people will tell you that it does not exist. Others that it cannot affect them, for example because they are 'Saved' and their house building was blessed by the church, but on other occasions might adhere to Luo 'traditions' (see e.g. Prince 2007 on 'Saved' Christians and *chira*). However it remains widely understood that *chira* is brought about when particular rules (*chike*) understood to enable growth are not followed properly, for example those which say that certain practices should be followed in order of familial hierarchy according to age and seniority, or those of marital responsibility. Thus, if a widow builds a house without a husband to 'put the door', or if a second son marries and builds a house in his father's home before the first born son has done so, it can bring *chira*. *Chira* is also understood to be caused by the breaking of particular taboos (*kweche*, sing. *kwer*) for example if a married son and his wife sleep under the same roof as his parents, *mano kwer kelo chira*; that is taboo, it brings *chira*.

However, the symbolic prosperity of the home is not only about the relationships that it represents and its potentiality to engender future relationships, nor the proper organisation of these relationships. Home (as I alluded to above) is also about material prosperity, and homes also act as markers of individual success and improvement and of a person's mastery of the modern world (cf. Green 2000). For Luo people, the ideal home is one which demonstrates success in both areas. The successful growth of the family is thus partly established by having and raising children and extending wider networks of relatedness via reciprocal obligation and support and the cultivation of indebtedness (Shipton 2007) as well as the proper buildings of homes (Prince 2004). However, markers of success also include sending children to school and in the longer term acquiring well paid and prestigious jobs which will allow them to send back remittances to their rural family.

For many of the Luo people I knew in Kagot district, and especially those who lived in the more rural area of Ramira, growth and prosperity of the home was also closely tied to the growth and prosperity of their gardens where they grew food for their family's consumption and for sale at local markets, thus generating both kinds of growth and prosperity; health (in the sense of well-fed healthy bodies) and monetary wealth<sup>53</sup>.

Balancing individual success and prosperity with broader relational obligations to extended family has long been a point of tension for Luo people (Parkin 1978: 214-42, Potash 1986: 61, Shipton 1989).

<sup>&</sup>lt;sup>53</sup> See (Whyte 1997: 13-4) for a similar understanding of prosperity among the Nyole of Eastern Uganda which combines fecundity and material wealth.

Sometimes these are incompatible processes; money earned selling ancestral land is considered "bitter" (Shipton 1989), and cannot be reintroduced to the generative cycles of the home, such as via the purchase of bridewealth, without causing death and sterility. However, the individual success embodied in educational achievement and material prosperity and the successful growth and nurture of networks of kinship are not necessarily mutually incompatible. They can be viewed as two sides of the coin of prosperity. For many Luo people, owning or managing a successful home is a process which involves having children and building relationships, but is also about becoming a particular kind of person. Later in the thesis I will argue that this double symbolism of home as both a marker of individual success and of broader relational wealth is key to understanding Home-Based Care, a governmental intervention to manage HIV/AIDS.

#### Hospital

Hannah Brown: Maybe you should go to hospital? Medicine for TB is free. Michael Okech: Medicine is free but the x-ray costs money<sup>54</sup>.

The paradox of hospital in Kagot is that whilst the District Hospital is recognised as a site of care it is simultaneously viewed as inadequate and unable to provide the care which should be available. At the time of field work, Kagot District Hospital represented the highest level of medical referral for the district population of around 250,000 people. However, although officially a 'referral hospital', in practice the hospital was used mostly by people who lived nearer to it than to the Sub-District Hospital, mission hospitals and smaller health centres in the district which also had inpatient facilities.

The district hospital itself is a chaotic splattering of small buildings across a large compound where mature trees provide welcome shade over grass which is kept short by the cows and goats that are allowed to graze around the compound. This is no planned district hospital where nurses move between wards along covered walk ways and wide verandas. Instead, the hospital is a rag-taggle collection of buildings; some new, others run-down, some repaired, others left to ruin, which reflect the different eras of the hospital (Dispensary, Health-Centre, Sub-District Hospital, District Hospital), the shifting health priorities of the Kenyan nation and its supporters; and the political trajectory of the district.

Limited dispensary-based medical mission work had taken place in this region from 1906 (Richards 1956: 10, 48) and the first hospital in the region was built by C.M.S. missionaries some 50km away at

<sup>&</sup>lt;sup>54</sup> Conversation in Ramira village, November 2006, translated from Swahili.

Maseno, in 1922 (Ibid: 47). Mission hospitals were built across the Central Nyanza region throughout the twentieth century, with the closest to Kagot built about 12km away; part of a Catholic mission built during the 1960s (Onyango-Ouma 2006: 397).

As elsewhere in East Africa, government interventions focused largely on medical care for Europeans and illness campaigns against infectious diseases among Africans in the early colonial period<sup>55</sup>, but the government increasingly built dispensaries with the aim of improving rural health from the late 1920s, although overall coverage was patchy (Beck 1970: 132-5, 1981: 15-23). The first government dispensary at Kagot was not built until 1953<sup>56</sup>. The building of the wards in the early 1970s added an inpatient facility to this small outpatient facility and allowed the upgrading of the facility from 'dispensary' to 'health centre'<sup>57</sup>, with the hospital later being upgraded to Sub-District and eventually District Hospital status, although these changes in status were not always matched with improved facilities.

In Kagot, people who knew the history of the hospital frequently romanticised the building of the wards, by emphasising the late Luo leader Oginga Odinga's role in "mobilising the community to donate the land" and "organising *harambee*", the Swahili term (lit. 'let's pull together') for the community fundraising and work romanticised by Kenyatta in newly independent Kenya. A volunteer counsellor at the hospital described with pride how he and his school class-mates had carried heavy stones up the hill to help build the wards.

#### Inequalities without

However, such descriptions had given way to the common contemporary perception of the hospital as run-down, inadequate and 'underdeveloped'. The dominant discourse used to describe the wards and the hospital in general had become one of dearth, despite the growing investment in HIV care and prevention services. The condition of the hospital was frequently used as a symbol to comment on the district's comparative underdevelopment and what was understood as the neglect of the region by politicians in power, perceived as punishment for its identification as an opposition stronghold, as discussed in Chapter One.

<sup>&</sup>lt;sup>55</sup> For example sleeping sickness (Geissler 2005)

<sup>&</sup>lt;sup>56</sup> Interview 24/11/06

<sup>&</sup>lt;sup>57</sup> These categories date from the colonial era. For a contemporary definition see 2.2.1-2.3.3 in (Muga et al. 2005)

Partly because the hospital had never been planned as a district hospital and had been upgraded in institutional status over time, it did not have the feel of other district hospitals in Kenya and was compared unfavourably to them. In the District Hospital of the nearest neighbouring district, for example, there were approximately three times as many beds in the government wards, which were larger and more open than the wards at Kagot. This neighbouring hospital also had facilities for isolating very sick patients and rooms for private patients. Work on new wards and a large outpatients department at Kagot had been started in the 1990's and was underway again after coming to a halt for around a decade following corruption allegations, stolen funds, and a large debt owed to the contractor<sup>58</sup>. By the end of my fieldwork period (May 2007) a new outpatients building was in use but little progress had been made on the building of the new wards. Meanwhile, among hospital staff the daily failings and shortcomings of the hospital were partly managed by engaging in a discourse of dearth in which Kagot was posited as not a 'proper' hospital and things "do not happen as they should," rather than through a critique of medical practice in the hospital which might have brought the practices of particular individuals under the spotlight.

### Inequalities within

Within the hospital a complex system of charges existed, with some items provided for free and others at a range of different costs. This complexity made it difficult for patients to know when they were supposed to pay and when not, a confusion which some staff took advantage of. Although I never witnessed any attempts by hospital staff to do so, it was widely commented outside of the hospital that some members of staff made illegal charges for tests, medicines and other services, to top up their pitiful and irregular salaries. Meanwhile, many of the staff at the hospital ran private medical practices or pharmacies, some showing up to work only intermittently around these other obligations.

Moreover, within the hospital there was great disparity of available resources across different sites and over time. There might suddenly be a huge influx of mosquito nets as an incentive for involvement in an immunisation campaign, for example, which could be and often were quietly diverted to meet other needs in the hospital. However, during the time I worked there, only half of the beds on the wards were equipped with nets and many of those were broken. It was often aid agencies who determined where priorities lay and where resources should be directed; the large

<sup>&</sup>lt;sup>58</sup> One of Kibaki's first moves after winning the 2002 election was to recommence work on all stalled construction projects for government buildings.

boxes in the hospital store room emblazoned with their logos. The arrival of drugs, test kits, laboratory materials and other hospital resources was never reliable, and although such items usually arrived eventually, there was almost always something missing which prevented staff from working according to guidelines. These shortages forced staff to improvise treatment or meant that patients had to purchase items necessary for their treatment outside of the hospital.

In general, those areas associated with HIV/AIDS interventions received more money and attention than other areas. This was particularly true of the VCT (Voluntary Counselling and Testing) Centre, which had brand new office furniture, including a large desk with a posh swivel chair. A new extension to this three-roomed building was being built by JICA, the Japanese government aid agency. Elsewhere, in the Mother and Child Health clinic, there were trained peer-counsellors and two extra full time nurses employed in the PMTCT (Prevention of Mother to Child Transmission) programme, their salaries paid by NGOs. This was in addition to the newly renovated Patient Support Centre, where people received HIV care including ARVs. Like other areas of the hospital, these sites of HIV/AIDS interventions experienced problems of understaffing, lack of resources, poor quality of buildings and so on. But the point is that relative to other areas of the hospital they were clearly much better resourced. The unequal spread of resources around the hospital thus spoke of the growing influence of NGOs and foreign funding bodies in Kagot as well as the exceptionality of HIV/AIDS as a disease requiring specialist forms of intervention.

Compare the shiny new VCT sign with the sign board for the whole hospital:



Figure 10. Signboards outside Kagot District Hospital

Karen Booth (2004: 109-11) describes a similar situation in a small health centre in the outskirts of Nairobi during the 1990's. Here, certain aspects of health care, particularly family planning and STI treatment were well funded by international donors and supported by research and training, while others, in this case almost all curative services, were woefully underfunded to the extent that people did not even associate the clinic as a place to receive such services. The clinic was no longer in the service of supporting 'general health' at all.

### Hospital as a domain of care

Despite the obvious inadequacies of hospital care and the costs of treatment to patients and their families, there were still long queues of patients waiting to receive outpatient care at the hospital every morning and it was rare that there were more than a handful of empty beds in the wards. Many women went to hospital when they were pregnant. Attending at least once meant that they received a maternity card which seemed to act as an insurance procedure. If they ended up having to

deliver the baby in hospital their prior attendance at the ante-natal clinic demonstrated that they were responsible mothers. Later, after giving birth, ante-natal cards were turned into child health cards when women brought their babies for weighing and immunisation.

Otherwise, most people only went to hospital because they were sick, often very sick. Deciding to take a sick person to hospital was not a decision which was taken lightly. Both in Ramira and Kagot town, people often waited some time before taking a patient to hospital in the hope that they would improve without costly outside intervention. People tried to cure themselves by using herbal medicines (*yath Nyaluo*) which were prepared, usually by women, as infusions which were drunk or washed in, usually from plants which were growing around the family home and which could be freely picked. Sometimes they searched out people who were particularly knowledgeable about herbal medicine. Often, people bought medicines from local pharmacies. If these interventions failed, they might decide to attend hospital (cf. Geissler and Prince 2009: 620-22).

A trip to hospital was almost never an activity undertaken by a person alone because it necessitated family members to assist with transport to and from hospital and also to raise money to pay for medicine and treatment (cf. Janzen 1978). As I discuss in Chapter 7, family members were also required to provide full-time care to people who were admitted on the wards. "You cannot go to the hospital with an empty hand [i.e. without money]," my informants told me frequently. These debates, over when and whether to go to hospital were often traumatic and underlined power differentials within families. Emily Obonyo told me how she had lost two young children in the same way. When they sickened, began vomiting and suffered from diarrhoea she began suggesting and later begging her husband to take them to hospital. "Just wait a bit," he kept saying. She waited, and twice her child died.

With the arrival of ARVs at Kagot District Hospital, hospital had changed its significance as a domain of care in relation to HIV/AIDS. When I spent time in Kagot in 2000-1, people suffering from HIV/AIDS did make use of hospital services, and often spent vast sums of money on bio-medical treatments in an effort to recover, in addition to other kinds of therapies. However, special interventions to deal with HIV/AIDS were almost completely non-existent. By the period of this fieldwork, ARVs were part of a whole range of new interventions in HIV care. It was now possible to get an HIV test in the Hospital. One could see the results appear in front of one's eyes; waiting to see if the second red line would appear on the thin test trip. Gradually, HIV interventions had come to influence all areas of hospital practice. In the ante-natal clinic women were offered routine HIV testing, and most chose to have it. For those who tested positive, there were drugs to try and prevent transmission to their unborn children. But if they did pass the virus onto their children, there was ongoing care for them, too, including some paediatric ARVs. Additionally, there was a TB clinic, where patients collected drugs each month and were offered an HIV test. Again, on the wards, people whose conditions were suggestive of HIV infection were offered a diagnostic test<sup>59</sup>, and were referred to the Patient Support Centre when they left hospital.

Spoken about together, these new initiatives seem much more cohesive than they were experienced by patients on a day-to-day basis. It is not an overstatement to say that many patients died because these systems failed them. Many women who tested positive during ante-natal care never came back for further treatment. Patients "got lost" when they were referred from the wards and the TB clinic to the Patient Support Centre. Diagnostic testing was frequently not carried out on the wards because there was no one to do it, or the staff on duty had not been trained in how to do it, or because there was no room free in which to do it. Angelica, a young woman whose admission to hospital I describe in chapter 7, had been admitted previously with an AIDS-related condition. The doctor had requested an HIV test but it had not been done and it was not until her readmission that she was finally tested. Had she been tested and started taking ARVs after this first period of admission when she was just a little stronger, her story might have been quite different.

### Conclusion

Between them, home and hospital constitute the most significant domains of care for Luo people in the context of high levels of HIV in Kagot District. In this chapter I have introduced some of the key issues in circulation around these domains of care and considered how Luo people understand and talk about those practices which I gloss as care. The remainder of the thesis uses ethnographic analysis to consider in more detail some of the practices of care which coalesce around each of these domains of care as people manage the effects of HIV/AIDS on their lives, beginning, in the next two chapters, with home, and an HIV policy known as Home-Based Care.

<sup>&</sup>lt;sup>59</sup> Such testing was called Diagnostic Testing and Counselling or DTC.

# Chapter Three. Home-Based Care: policy as practice

### Introduction

In the last chapter, I contextualised home and hospital as domains of care against the background of the HIV epidemic in Kagot. In Kagot District, as elsewhere in Sub-Saharan Africa, medical care for HIV/AIDS has until recently been limited to treating opportunistic infections and limited palliative interventions. Much, if not most of the care that has taken place in response to HIV/AIDS has taken place at home. Illife, writing about the history of the African AIDS epidemic suggests, "Everywhere in the continent, it appears, families had a unique and morally inescapable obligation to care for their own" (2006: 102). He goes on to cite a 2004 UNAIDS estimate that around 90% of all care for HIV+ people in Africa was provided by family members (Ibid.). Even with the introduction of ARVs, home remains an important location of HIV and AIDS care. Partly in response to this, the home, and the kind of care which happens there, has become an object of government and international development intervention, in particular through a policy known as Home-Based or Community-Based Care.

This chapter and the one which follows are an ethnographic exploration of this particular policy. The main argument over the two chapters is that Home-Based Care is made to exist as a policy through the complex combination of practices and ideas that enact it and through the relationships between these varying enactments. These practices take place in the divergent arenas of people's homes, grass roots organisations, hospitals, NGOs, the World Health Organisation, the Ministry of Health and many more places besides these. However, my analysis focuses on the practices of Community Health Workers who were members of the Community-Based Organisation where I carried out much of my fieldwork, which I call Kagot Development Group. The chapter is divided into three parts. Part One outlines the ideology of Home-Based Care and introduces Kagot Development Group, along with some of the Community Health Workers who were members of the group. Parts Two and Three examine what doing Home-Based Care looks like ethnographically by following the practices of members of Kagot Development Group as they do Home-Based Care. I argue that their enactments 'embedded' and 'professionalising', which I discuss in Parts Two and Three respectively. I conclude

the chapter by considering how these different enactments are made to work together to produce a policy.

In the chapter which follows this one, I suggest that Home-Based Care is also relationally multiple. I argue that the practices which enact Home-Based Care come together within an elaborate network of *ideas* about Home-Based Care. I show how these are relationships and ideas which make Home-Based Care *work*, in the sense that people want to do it. I describe how ideas about Home-Based Care constitute a web of relationships and practices which have moved via people and objects through particular institutions and spaces. Using an analysis which combines ethnographic and historical material, I emphasise the longstanding nature of the promotion of a particular kind of gendered individual via the 'development' of home, and how these projects have combined with the idealisation of motherhood and a gendered division of labour. My argument, against those who see Home-Based Care as an expression of new forms of neo-liberal governmentality, is that the particular ensemble of ideas and practices which comes together around Home-Based Care is in many ways not new. I argue that it is partly the longstanding existence of very similar ensembles of practices to those which are involved in doing Home-Based Care that makes Home-Based Care legitimate and appealing for who do it.

Across the two chapters, I argue that key to understanding the motivations of those who volunteer their time to do Home-Based Care, is in the recognition that it combines the two aspects of domestic prosperity that I identified in the previous chapter; doing Home-Based Care is a way towards achieving individual distinction and increasing productive relational networks. This is partly because of the way in which Home-Based Care is organised; using female volunteers who are trained to offer advice and support to others. This process allows those who work as volunteers to demonstrate themselves as 'developed', whilst at the same time the access to valuable resources provided by such projects allows volunteers to build up new (and strengthen existing) networks of indebtedness and obligation to others. By imagining home as a site to be improved and managed, Home-Based Care interventions (like the colonial endeavours which preceded it) have thus meshed with Luo understandings of home as a site of growth and the improvement of the family and the progress of the individual.

# Part One: Introducing Home-Based Care

### Home-Based Care

Health policy literature describes Home-Based Care, also referred to as Community Home-Based Care, as "any form of care given to ill people in their homes" (WHO 2002: 6). Despite this, in Kenya as elsewhere in Africa, the term Home-Based Care has come almost invariably to refer to the care at home of people who are suffering from HIV/AIDS related illnesses, through a recognised set of interventions. Home-Based Care initiatives have become an important response to the HIV/AIDS pandemic in Kenya as in other African countries, and community and home-based caring strategies have increasingly been written into policies on HIV/AIDS intervention (Akintola 2004, Iliffe 2006: 110-1, Ministry of Health 2002, Ministry of Health 2005b: 24-5, WHO 2001, WHO 2002).

By the year 2000, a number of NGOs in Nyanza province had begun organising Home-Based Care activities as an HIV response, mostly working through the Ministry of Health, using Community-Based Organisations, particularly those that described themselves as 'women's groups'<sup>60</sup>, as collaborative partners. The numbers of such interventions mushroomed in 2001 when the Kenyan government began to fund such groups directly through NASCOP (The National AIDS & STD Control Programme), via DACS and CACS (District and Constituency AIDS committees) (Ogot 2004: 83-8, 96-9). Although Home-Based Care initiatives are widely understood to have begun in the so-called 'third sector', from the beginning they were heavily involved with and often worked through the Ministry of Health.

Home-Based Care programmes in Kenya typically include the training of a 'Trainer of Trainers', usually a medical professional such as a clinical officer or nurse based at a rural health facility, or a community leader, who supervises the training and/or activities of Community Health Workers. In this model, clinical care is distinguished from community or family-based care, and it is assumed that there exists beneficial potential in linking these two types of care, or more specifically in managing care at home through a clinical model of HIV care. The Community Health Worker is trained in supporting particular aspects of nursing at home. Community Health Workers are also imagined as assisting with what are often referred to as the 'social' needs of patients, which include counselling, income generation and nutritional advice (Ministry of Health 2002, 2006a, 2006b).

<sup>&</sup>lt;sup>60</sup> This data comes from personal experience of working for such an NGO in this area between 2000-1.

More recently, with the arrival of free anti-retroviral therapy, Home-Based Care has become part of a wider set of strategies known together as 'comprehensive HIV care' (Ministry of Health 2005a: 46-57) and 'care across a continuum' (Ogden et al. 2006, WHO 2000: 5.4), with a concurrent shift in emphasis away from a good death and appropriate terminal care, to ambitions around 'living positively', including drug adherence. Community Health Workers are understood to embody the link which allows care to be "extended from the health facility to the patient's home" (Ministry of Health 2002: 6); assisting in the clinical management of HIV care by tracking, introducing and referring patients to hospital support centres where they receive medication.

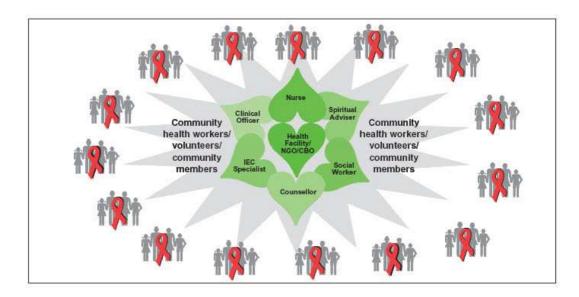


Figure 11. "A Possible Home Care System" (Ministry of Health 2006a: xi).

### Kagot Development Group

In a pair of small rooms behind a row of shops in Kagot town lie the offices of a small Community-Based Organisation. Hand-written posters and faded health education materials line the walls of the single storey building; a sewing machine sits in one corner; large sacks of maize are piled high in another next to a stack of plastic chairs ready for use at meetings and by visitors. A couple of young women share stories while one fills out a tedious record sheet. Another woman enters and greets them, asking them to decipher a prescription she has for the sickly baby wrapped tightly on her back. In dribs and drabs more women arrive to attend a meeting as the sheets of *mabati* (Swa.) – the corrugated iron that forms the roof – slowly cook the air inside the small rooms. Kagot Development Group was formed by a small group of local residents in 2001, with two women the main driving force behind both the foundation and the ongoing management of the organisation. Elizabeth, who had fashioned the smaller of the two rooms into her office, was responsible for the day-to-day running of the group. The second woman, Philomena, was a retired teacher and widow who owned a large bar-cum-hotel and a number of rental properties in the town, including the one which the organisation used free of charge. She was mostly absent from the office but played an important role in the writing of reports and funding proposals and meeting guests and visitors. Philomena was described by Elizabeth as the group's "local donor". Both women were openly 'living positively' (i.e. with HIV) and told me that they had started the organisation, "because we saw the way that the youths were dying." Elizabeth explained, "From that time we have been doing homebased care, although we didn't realise at first that was what we were doing we were just doing it, but after time we came to know that it was home-based care."

For Elizabeth, home-based care was by definition a broad concept under which she could provide counselling, nutritional advice, make school uniforms and raise money for school fees for orphans dispense drugs from her office and encourage income-generating activities. All the work that went on in the organisation was completely voluntary. Neither Elizabeth, Philomena, nor the two 'Office Girls'<sup>61</sup> who worked full time for the organisation received a salary for their work.

The women who have begun to arrive at the offices are members of a group referred to interchangeably as the 'support group' and the *Nyamreche* (sing. *Nyamrerwa*), Community Health Workers, coming to attend their weekly meeting. Most of them are widows; older women who do not have very young children to care for at home. Many of them are themselves HIV+. They come dressed in long skirts or dresses, cheap 'rubbers' on their feet (plimsolls – so called because of the rubber sole) which carry the muddy signs of early morning farm work and the walk from the village. Their heads are covered by large scarves tied neatly in knots at the back of the neck. In their bags they carry a *leso*, a piece of fabric upon which they can sit and rest, or cover up the few items of food that they have bought at the market, a few coins tied up in the corner. A few have received a partial secondary education, some little schooling at all. They speak to one another in Luo, the local language, but a few of them are also proficient speakers of English or Swahili. Most hail from a village

<sup>&</sup>lt;sup>61</sup> I found the term 'office girl' mildly offensive and once (only half jokingly) suggested to Elizabeth that she call the young women 'trainee managers'. I took her reluctance as demonstrative of her desire to create for herself a particular kind of feminine authority within the organisation (see Chapter 4.). In *Dholuo* the young women (aged around 18-20 years) were called 'ofis girls'. In the writing that follows I use my informants' label, and lose the scare quotes.

about 5km from the town, Ramira, which became the locus of much of my ethnographic research. Just over half of the group members have been trained as Community Health Workers to provide Home-Based Care<sup>62</sup>. When asked to define Home-Based Care, these women, like Elizabeth, emphasised the idealised concepts of domestic care which lie behind the model and would often say, "Home-Based Care is not a new thing, it has always been there. It is just the care that people are giving at home."

### **Community Health Workers**

Beatrice was widowed in 2002 when she was in her late 30s. Recently married into Ramira village, her husband Onyango had died while the family were still living in the small grass-roofed house that, as tradition requires, Onyango had built in a single day when he first moved out of his parent's compound to start his own home. He had not had chance to build a larger permanent home before his death. In the context of what Beatrice called "our disease", where our implied 'Luo' and disease 'HIV/AIDS', people in Ramira had become experts in reading the signs of approaching death that characterised the culmination of the long and painful sickness of AIDS. Once they had accepted the inevitable, it was common to pre-empt death with strategies that would allow a person a respected burial. The building of a small one-roomed hut on one's own homestead allowed men to be buried as men (*Jaramira*) rather than sons (*Wuodramira*) of the village. So it was that sick men often struggled to build homes they knew they would be unlikely to live in for long, sometimes dying even before the mud walls had been made smooth.

With Onyango gone, Beatrice was left with five sons to bring up alone. She had brought the three eldest boys with her when she married Onyango, the products of previous marriages that had taken her to Nairobi and Mombasa before she married in Ramira and they became Onyango's sons. At Onyango's death she found herself *piny kabisa* (Luo/Swahili, "completely down"), living in the tiny grass-roofed house which symbolised to herself and others her desperate situation<sup>63</sup>, unwell, impoverished and without the strong networks of support that women build over time in their marital homes. Beatrice's relationships with Onyango's family were difficult. Perhaps, I wondered, this was because they blamed her for bringing illness to Onyango. In addition, as Beatrice herself explained, people in Ramira had thought she would "run away", perhaps to begin a new relationship.

 $<sup>^{62}</sup>$  They were trained through a collaboration between Mildmay International (an NGO) and the Ministry of Health.

<sup>&</sup>lt;sup>63</sup> In Ramira, grass-roofed houses have come to symbolise poverty, while corrugated iron (Swa. *mabati*) roofed houses symbolise development and prosperity.

Her relationship with Onyango's elder brother Owuor, whose plot was immediately adjacent to hers, was particularly strained. He had tried to "chase her away" many times, for example by maliciously encouraging his cattle to eat crops which she planted, and by growing maize on a piece of land that according to tradition, should have been under cultivation by Beatrice's sons. The relationship was still sour when Beatrice introduced me to him in 2007 and no surprise – a recent argument between them had resulted in Beatrice reporting him to the police who had arrested him and forced him to spend the night in the cells at Kagot.

Beatrice had embraced the role of Community Health Worker, finding support in the relationships that she developed with the other women in the group, many of whom were also from Ramira village. She was genuinely grateful for material gifts she had received from the organisation and for the support she had been given in the difficult period following Onyango's death when she had become a member of the support group. Since receiving training as a Community Health Worker, she had begun to use this role to gain status in the village, building relationships with the other women in the group, strengthening existing relationships by extending the material resources of the organisation to her in-laws and friends and using the role to gain new clients. When I was with her, Beatrice regularly emphasised her position as Community Health Worker during introductions and interactions with others.

So it was that Beatrice's position in the village did not seem so precarious by the time I came to know her, in either economic or social terms. Her *shamba*, the small-holding which surrounded her house, was flourishing. With the help of her sons she had planted a range of crops which provided food for the family including maize, beans, millet, sorghum, and fruit trees. She also grew cotton for sale. The two older boys were involved in intermittent wage labour, and the younger three children were all at school; they had exercise books and uniforms. Although not wealthy (she was still living in a grass-roofed house, albeit one with two rooms), Beatrice had recently managed to build a *simba*, a house where her older teenage sons could sleep<sup>64</sup> and which would become the house of her eldest son and his wife once he decided to marry. She had a few goats, including one on loan from another women's group of which she was a member, which she would return after it produced a kid for her.

 $<sup>^{64}</sup>$  It is *chira* (Luo. taboo) for children who have reached puberty to sleep in the same house as their parents. In town houses the rule applies to the parents' bedroom rather than the whole house. Before Beatrice built the *simba* her sons were sleeping outside anywhere they could find a place, perhaps in relatives' kitchens.

Beatrice had also developed a mutually supportive relationship with her late husband's classificatory brother, Edward, who had 'inherited' [*tero*] her. Edward lived in his own home and farmed his own *shamba*. He brought Beatrice produce from this plot and gave her rides into Kagot on the back of his bicycle when she wanted to go into town. He provided her with companionship and sexual satisfaction. When I visited her again in 2009, Beatrice welcomed me into a newly built large house with a corrugated iron roof, one of the most important symbols of prosperity and success in Ramira. Being a Community Health Worker was interlinked with these other improvements in Beatrice's life.

Beatrice lived within walking distance of the other Community Health Workers of Ramira village with whom she shared the experience of being married into the same community<sup>65</sup>. The women often followed the convention of greeting one another with names that drew attention to their pre-nuptial homes, for example, *NyaAlego* or *NyaGem* (lit. Daughter of Alego, Daughter of Gem). Such greetings, combined with the convention of teknonymy, the naming of parents after their first born child, continually emphasised the relationships and links that each woman's marriage and motherhood had engendered for their shared community.

As close neighbours, sometimes relatives<sup>66</sup>, the Community Health Workers had intimate knowledge of one another's biographies as wives and mothers. With the exception of Elizabeth and the young unmarried women who worked for the organisation in Kagot town as Office Girls, who had also received training as Community Health Workers, all but two of the women in the group were widows. These last two women both had husbands who had migrated away from the region to work. All were past the age where they were involved in the hugely time consuming activities of bringing up very small children of their own.

I do not emphasise the widowed status of these women to suggest that it was the absence of husbands *per se* which allowed them the freedom to work as Community Health Workers. Such an analysis would suggest that men have a great deal of control over how women spend their day-to-day lives. The reality is that men and women live quite independent, autonomous lives, although women are completely responsible for all the household chores for the whole family, including cooking,

<sup>&</sup>lt;sup>65</sup> New marriages between Luo people are usually either virilocal or entail couples living in rented accommodation in Kisumu or Nairobi or other trading place.

<sup>&</sup>lt;sup>66</sup>Where women in the group were related they were either sisters (*nyamin*) who had married nearby one another or sisters-in-law (HBW; *nyiego*) but interestingly, never co-wives (also *nyiego*) who tended not to join groups such as this one together.

washing clothes and so on, as well as many farming duties – all of them time-intensive and physically demanding undertakings. Some men talk openly about beating women who do not perform these tasks 'properly'. However, men's control over women is often more complexly negotiated, particularly as women grow older.

Beatrice had been 'inherited' by Edward, but the English term suggests nuances of control and ownership which are absent from the Luo institution of *tero*. When Beatrice spoke of Edward it was clear she had been in control of the decision to begin a relationship with him, refusing his initial advances until he had made the many changes she demanded, including that he gave up drinking alcohol. Edward did not control Beatrice's movements and the institution of *tero* meant that Beatrice could send Edward away and end the relationship any time she chose<sup>67</sup>. Unlike Beatrice, many of the widowed women in the group had refused 'inheritance' altogether.<sup>68</sup>

While I have argued that it was not freedom from the oppression of husbands which enabled these women to become Community Health Workers, it is perhaps true that being without husbands reduced the amount of work that these women had to do around the home. More fundamentally however, what I would suggest is that the experience of becoming a widow made these women particularly appropriate candidates for roles such as that of the Community Health Worker. These women had close experience of death and many were themselves moving towards the end of the life cycle. This is partly what made them capable of dealing with the death and suffering of others (cf. Green 1997).

Moreover, as in Beatrice's case, many of the Community Health Workers were HIV+ themselves and some had begun their involvement in the group as clients who were supported when they were sick and had only later been trained as Community Health Workers. It has been noted many times in studies of the so-called 'traditional' healing sector in East Africa and more widely, that it is often a personal experience of illness which is the catalyst for a person's conversion to the role of healer (e.g. West 2006: 27, Whyte 1991a: 157). The experiences of these women are suggestive of parallel phenomena outside of this sector and of broader links between a person's ability to provide care and advice to others and their own gendered experience of suffering.

<sup>&</sup>lt;sup>67</sup> Although I should mention that many women felt immense pressure to be inherited, so it would not be true to say that such relationships are always freely entered into.

<sup>&</sup>lt;sup>68</sup> These women were mostly 'Saved' Christians. See Chapter 2.

### Part Two: Embedded Enactments

### Policy as practice

This chapter explores Home-Based Care via some of its practices. In dealing with the practices that make Home-Based Care, this chapter begins by turning on its head the analytic separation between policy and practice that is frequently employed both in ethnographic writing and more widely in policy and development literature, in which policy ideas are seen to trickle down from global or national levels and to provide a contextual background against which practices are played out as a 'local' interpretation or manipulation.

I begin from the perspective that a particular policy cannot be not imagined as existing outside of a reality upon which it is made to act. It is in the reality of practice that policy is brought into being. In Home-Based Care these practices include the production of documents, the use of particular terms and language, the development of home care plans and gifts of maize or high protein flour to sick people. I do not suggest merely that policy is a dialogic, relational activity between those who engage in these diverse enactments, but go on to argue that policy is a multi-domain organisational practice which can be studied from the perspectives of these different domains as it is enacted through practice. The Community Health Workers at Kagot Development Group enacted Home-Based Care; organising what was, and what was not, Home-Based Care and how it should be done. These enactments were not just responses to policy initiatives designed elsewhere; they enacted Home-Based Care. They enacted a policy.

The position I take up is well-established in the work of those who have rejected the notion of the social as an explanatory domain (Latour 2005) and more generally an opposition between surface and deep reality (e.g. Mol 2002: 37). I argue that rejecting policy as a trickle-down agent of change is also a way of taking seriously divergent kinds of interaction that help explain why certain changes happen and particular ideas gain currency. I take seriously what Philomena, Elizabeth, Beatrice and the other Community Health Workers told me when they said, "We are doing Home-Based Care." My interest is to consider some of the multiple methods by which a particular policy is engendered with agentive qualities, using ethnography to criticise the (spatialised) assumption that policies are made somewhere (else) and brought in to act upon a particular place (cf. Ferguson and Gupta 2002).

In following this argument, I make a playful move with Mosse's (2005: 2) suggestion, "What if the practices of development are in fact concealed rather than produced by policy? What if, instead of policy producing practice, practices produce policy...?" What Mosse is getting at here is an interest in *how* (rather than whether) development works and in the kinds of practices that make certain policies legitimate at certain times. Characterising writing on development as generally either *instrumentalist* (rational problem solving) or *critical* (as concealing hidden powers of dominance (e.g. Escobar 1995, Ferguson 1990)), Mosse argues neither approach has satisfactorily investigated the practices of development implementation. He argues for a rich ethnographic approach to examine the "relationship between policy discourse and field practices" (Ibid.).

However, when Mosse talks about the practices of development, he invokes exactly the kind of spatialised model I aim to critique here, where policy makers are seen to 'make' policies which are diverted/appropriated/interpreted/implemented by field staff. Indeed, however rich the ethnographic analysis in which Mosse details the shifts in the legitimacy of the policies and projects he describes in India, I suggest here that it is worth questioning the assumption that underlies his argument – the existence of these two separate realms, of policy and field practices.

Maybe it is worth reframing his suggestions. Firstly, perhaps the practices of development are concealed rather than produced by policy, in the sense that we become tempted to see policy as a set of ideas and implementation strategies outside of, often 'above' (Ferguson and Gupta 2002) the sites upon which they are designed to act. In other words, the broad range of practices that make policies are concealed by a model that assumes where and how policies are made. Secondly, perhaps practices produce policy in the much wider sense that policies only exist via the doings of them; consisting of a multitude of activities which cannot easily be separated into different 'levels', or divided into policy discourse versus field practice, and perhaps never really make a single coherent object, but rather a number of different but overlapping objects (cf. Mol 2002). From such a starting point it is difficult to talk about a policy like Home-Based Care as ethnographic context. Instead Home-Based Care becomes an object (or set of objects) available for ethnographic study via the many practices that make it happen, which include the use of linguistic terms, documentary procedures and home visits.

It is by following the mobile practices and ideas which cohere around and "enact" (Mol 2002: 32-6) specific policies that we can gain a sense of what policies 'are', rather than by beginning with the categories of a policy like Home-Based Care which are often *produced* in complex and problematic

ways by a particular policy, as though these categories, such as 'home' in the case of Home-Based Care, might offer us the parameters within which practice happens.

I borrow the term 'enact' from Annemarie Mol, whose study of atherosclerosis in a Dutch hospital examined the practices that enact (i.e. create through practice) the disease atherosclerosis in different sites within the hospital; under the microscope, in the laboratory, the operating theatre, the consulting room. Mol's analysis foregrounded practice to allow her to make an important ontological argument about the multiplicity of objects;

"If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead, objects come into being – and disappear – with the practices in which they are manipulated" (Ibid.: 5).

These enactments, Mol argues, do not produce different versions or aspects of the same diseaseobject, but are *different objects* made to cohere (or to stay apart) through a variety of techniques of coordination, translation, distribution and inclusion. Following Mol, I would also argue that what is made through enactments of Home-Based Care is a series of objects, rather than different versions of a singular Home-Based Care, which are made variously to cohere and remain apart through certain techniques and practices.

Just as a different atherosclerosis was enacted in different sites within the Dutch hospital, the complexity of the networks of legitimacy and circulations of ideas around Home-Based Care allowed my informants within Kagot Development Group to enact two quite different models of Home-Based Care even as other kinds of Home-Based Care were enacted by Mildmay, the NGO which funded them, and by the Ministry of Health. Moreover, I argue that one of the principal reasons why Home-Based Care worked as *a policy* was precisely the existence of multiple ways in which Home-Based Care could be enacted.

### Home visits

In this section I consider in some detail the kind of care which Community Health Workers provided during visits to those whom they referred to by the English term 'client', but by the much broader term *jatuo* [pl. *jotuo*], literally meaning 'sick person', when speaking in Luo. This section of the chapter adds contextualisation to work which has drawn upon the notion of clientelism to make sense of the strategising of those implementing comparable social welfare programmes, such as the 89

Community-Based Distributors (CBDs) described by Kaler and Cotts-Watkins (2001). These authors argue that CBDs advantageously, used "their position and their limited access to resources to cultivate a client base among local women" (Kaler and Cotts-Watkins 2001: 256). My ethnographic analysis shows that similar attempts by Community Health Workers in Kagot to create a client base were highly influenced by existing relationships and obligations. My argument is that Community Health Workers developed a client base by providing a form of care at home which was embedded in existing relationships, norms of visiting, gift giving, assumptions about obligation and reciprocity and networks of medical knowledge in and around the home.

When I began fieldwork at the organisational office in Kagot, the Community Health Workers kindly worked together to write a work-plan for me to visit clients with them. So it was that I began visiting clients with each woman in turn, and, as I built stronger relationships and friendships, made more frequent visits with those Community Health Workers who were particularly keen to show me their work. The clients of Community Health Workers were both men and women, ranging from the relatively well-off to the desperately poor, the reasonably healthy to the dying. Some Community Health Workers had almost ten clients; others only one or two; while a couple told me, "pok aseyudo", I have not yet found any.

During these early visits the situation would generally be quite formal. Sometimes the Community Health Worker would tell me something about their client before entering the home, framing the visit within a moral agenda of testing, adherence to treatment regimes and a discourse of "living positively", by which they implied being open about one's HIV status. For example, they told me, "She is sick but is refusing to go for the test" or "He was really down, I'm the one who talked to him to go for the test and now he is taking those drugs he has really come up." Less frequently I heard, "She doesn't want to talk about HIV/AIDS, only about TB." In all cases, politeness required that we call out *Wadonje?* (Luo. May we enter?), before entering the home. Once we entered the client's home we might pray (depending upon the religious persuasion of the Community Health Worker and/or the client) before sitting down together. Then the Community Health Worker would ask the client to tell me his/her medical complaint and largely let the client speak for him or herself, the visit becoming an opportunity for the client to tell the story of their illness;

**Maurice** (a retired teacher and ex-area councillor): So I was sickling for 2 ½ years, my legs were swelling and very much painful and she [**Anne**, the Community Health Worker], convinced me that I should go for the test and the test was positive, HIV+. Now after I

tested I decided to go to the district hospital PSC [Patient Support Centre] whereby they gave me some medicines, three varieties which I am taking one is finished and I'm supposed to go and get more on 4th. **Maurice** shows me two bags of medicine containing Septrin and multivitamins, along with his support centre card.

**Lillian** and I enter a large house belonging to her client's grandmother. The grandmother moves to another chair to give us her best seats telling us, "These are the seats for guests." The granddaughter sits on the floor and tells **Lillian** in Dholuo that she has been taking TB medicine for two weeks now and she is feeling so much better, she is feeling stronger and more active. Then the girl gets her medicine down to show me. She says that they told her to go back after two weeks because her weight was so low. She says that the main problem now is that she is hungry all the time. Before we leave **Lillian** gives the old woman (who is not her 'client') some Paracetomol for her aches and pains.

**Persila** and I enter a compound and go into a small house, the first on the left. The house is divided into two rooms. We wait in the sitting room for the woman to come out of the other room through a doorway which is covered by a curtain. She comes through the curtain and we all stand while **Persila** prays. Then we sit down and the client introduces herself as **Eunice Okech**. **Eunice** sits in the chair opposite us. She tells me that she is coughing and has terrible pain in her chest. I ask if she has heard anything about TB and she says that she is on TB medication and she also goes to the support centre where she is given ARVs. She also complains of an itch over her body. She goes into her bedroom and comes back with a small cloth bag where she keeps her medicines and the cards from the hospital. In fact there are no ARVs, only Septrin and multi-vitamins. **Persila** says that she thought Eunice was on ARVs, she advises Eunice to go for a CD4 test and pulls some Piriton tablets out of the home care kit<sup>69</sup> to give her for the itching before we leave.

These brief extracts from field notes during September and October 2006 show some key themes of home visits. In many respects, visits were modelled upon wider norms of giving and receiving visitors. However, Community Health Workers also emphasised the importance of recording the visit, often looking at my note book and emphasising, "write down her name." The act of writing a name became a symbol of potential future connections and a possible path down which resources might flow, as well as a sign that the person's experience and opinion was of value and deserved recording. The same was true of the opportunity that the Community Health Worker gave the client to tell their

<sup>&</sup>lt;sup>69</sup> A bag containing medicines and equipment for Home-Based Care.

story to me in their own words. Additionally, clients were often keen to show me their medication and health documents. Doing so was both physical proof that they were linked into the formal processes of care at the hospital as well as the chance to receive reassurance that they were getting proper care.

The care which Community Health Workers provided during home visits could largely be divided into three aspects. The first was the giving of advice (referred to as 'counselling' by those Community Health Workers who spoke English). The second was the giving of objects which included food and medicine. The third aspect was being there and demonstrating love or care through attention. Community Health Workers did not provide intimate care to clients, which was considered to be the responsibility of very close female relatives. They did sometimes offer advice regarding cleaning a wound and dealing with bodily fluids and they might try to obtain gloves for the caregiver. However, like the nurses who worked on the wards of the district hospital (see Chapter 7) Community Health Workers did not cross the boundary that delineated the familial care of the very sick body as the work of very close family members. When Community Health Workers did provide extra support to sick people it was always in the form of house work (such as collecting water or firewood) rather than hands-on physical care.

By far the most common intervention that Community Health Workers made was persuading someone to go for testing based upon an analysis of their symptoms. A broadly shared knowledge existed across the community about the relationship between the presentation of certain symptoms and HIV/AIDS, the most notable being severe loss of weight and the persistent cough of tuberculosis. In the case of the Community Health Workers such knowledge was augmented through training as well as personal experience. They were most likely to suggest someone go for testing when the appearance of particular symptoms combined with the death of a spouse. During this often lengthy process of persuasion they became 'supportive others' in trajectories of care which cut across home and hospital (see Chapter 5). In cases where testing led to a successful course of treatment, people genuinely recognised the interventions of Community Health Workers as life-saving, telling of great indebtedness to the Community Health Worker for being "the one who convinced me to go for testing", as in the case of Maurice, who is quoted above.

### **Embedded** Care

Some of the Community Health Workers became friends and to my delight began to include me in other aspects of their lives so as to teach me "how Luo people live" (*dak*). Beatrice became an informal research assistant who helped me gain access to other homes in the village and who translated the Luo phrases which escaped me. As I became involved in other parts of these women's lives, attending funerals, planting maize in the *shamba*, visiting their children's schools and their friends and family, I became aware of how difficult it was to make a distinction between the visits they made as Community Health Workers and the other kinds of interaction that they had with their clients. Outside of the formalised situations of the type initially presented to me as 'Home-Based Care', there was often nothing obviously 'medical' about Community Health Worker visits. Indeed, a person's sickness was not usually the primary focus of a meeting between the Community Health Worker and her client, but rather a potential aspect of it.

A Community Health Worker could pass by, take tea and catch up on the news of the client, news which might include how the drugs were making her feel or what had happened at the last trip to the clinic, or how the constraints of day-to-day life had stopped her from attending clinic, but equally might not include any of these things. Neither did Community Health Workers set out to make special visits to their clients (when not showing a visitor around) but tended to see them in the context of other activities. They might see their clients as they were passing to fetch water or ask for news of them from relatives whom they bumped into on the road or at the market, embedding their questions within a common set of greeting practices that asked after the health of a person and their whole family, and which did not draw attention to a particular person's illness<sup>70</sup>.

What became clear was that it was the *relationship* between the Community Health Worker and her client which was central to understanding Home-Based Care. Indeed, Community Health Worker's clients were usually first and foremost kin or friends, relationships which took precedence over any other interactions. And because this relationship was not necessarily tied to the home but moved with the people that made it, it made sense that many of the practices which Community Health Workers considered to be Home-Based Care also did not happen at home. Home-Based Care happened in the home, on the side of the road, by the pond where women collected water, and via mutual friends or relatives at community gatherings. It did not even necessarily take place directly

<sup>&</sup>lt;sup>70</sup> As I mentioned in the introduction, a common greeting pattern is *Ingima*? (Are you well), *Angima* (I am well), *Joodi gingima*? (Are people from your home well?) *Gingima* (They are well).

between client and Community Health Worker. For example, Jocinta received news of her client Judith, from Judith's mother-in-law when she went to Kagot town and met her in the small *hoteli*<sup>71</sup> in the market where she sold *nyuka* (a thin porridge), or on Sundays when they met at church. She rarely visited Judith at home.

If it was not always clear where Home-Based Care started and ended, in terms of the sites in which Home-Based care happened, this was further intensified by the fact that the Community Health Workers often tried to extend their services to people not obviously HIV+, flouting the clear policy of the donor organisation which supported Kagot Development Group. The first time I went to their home in particular, the women tended to introduce me to everyone they knew suffering from any kind of illness. On the first day I went out with Beatrice she introduced me first to Edward, the brother-in-law who had 'inherited' her (*jater*) who had a rash on his leg, two orphans<sup>72</sup> from a neighbouring compound who had recently lost their mother when she died in childbirth, another orphaned girl living with her grandmother and an old man with a swollen foot. Then we met a woman who had been very sick but had tested negative for HIV (whom people were saying was ill with *chira* after breaking rules of hierarchy by cooking before her mother when they returned home after a funeral), and lastly an old woman with a band of herpes zoster around her hip.

Beatrice had a relatively high level of general education and specific knowledge of HIV. She herself was HIV+ and talked about being in a "discordant couple" and suffering from "opportunistic infections". Her inclusion among her clients of people who were not HIV+ was therefore not the result of misunderstanding. Firstly, Beatrice recognised that a HIV diagnosis was complex territory. The old woman with herpes did turn out to be HIV+ although both she and Beatrice had thought this very unlikely because she was old and had "left all those things [i.e. sexual intercourse] long ago." Beatrice also left me with the impression that she thought the young woman who had tested negative was perhaps really positive. And perhaps her discordant partner had been exposed to the HIV virus.

However, what Beatrice also seemed to be rejecting was the notion that people with HIV deserved to receive special care while others who were sick did not. Like members of the South African community interviewed by Meintjes and Giese (2006) about the vulnerability of *all* children *vis-à-vis* 

<sup>&</sup>lt;sup>71</sup> Swahili, meaning hotel. In Kenya small eateries and restaurants are referred to as hotels.

 $<sup>^{72}</sup>$  In this part of Kenya, as elsewhere, a child is referred to as an orphan when they have lost one, not necessarily both parents.

those defined as 'orphans' in the context of interventions which focused exclusively upon the latter, Beatrice seemed to be, "locat[ing people's]...experiences of vulnerability firmly within a broader context of poverty and hardship" (Ibid. : 420). In doing so, Beatrice was also using caring practice to 'make' a version HIV/AIDS in which the illness was not so very different from the other illnesses and problems afflicting people in her community and where the care of people who were HIV+ was embedded within other, broader kinds of care<sup>73</sup>. Seeking comparisons with others' practices, I asked Judith (who blamed herself for becoming sick and possibly infecting her husband), if she felt as though her in-laws blamed her for bringing sickness to the family. Her reply was quick and categorical. "My in-laws? My in-laws do not blame me...They say that this is just the disease which is going around, that it's a type of disease that has come that is killing people in Kagot."

Practices which attempted to share out the resources and attention meant only for HIV/AIDS can be considered as attempts to reduce the cruelty of stigma in a community where so many are affected (and where those who are not affected may still be suffering from illness and poverty). These practices contest aspects of policy interventions which emphasise the exceptionality of HIV/AIDS in ways which label certain kinds of suffering as more deserving than others. An argument that runs through this thesis is that care is not simply a response to a particular disease, such as HIV, but is also a set of practises which dynamically constructs and shifts ideas about illness. In a sense illness is 'made' though care. As Community Health Workers carried out this embedded model of Home-Based Care they helped to make a particular illness, HIV/AIDS, which at certain times and for certain people, was not so different from other illnesses which affected people locally.

I do not argue here that stigma of HIV/AIDS did not exist in Ramira. On the contrary, there were many occasions when Community Health Workers' attempts to counsel people who showed the signs of AIDS were met with outright rejection and even anger. One such refusal came from Min Dot, who ran a successful small business selling small items of food from her front room but whose weak body could increasing hardly carry its own weight. Her attempts to continue her business as her body decayed led to cruel jokes from the Community Health Workers, many of whom had suggested that she go for testing and treatment. "Have you seen a skeleton is going to Kagot to buy tomatoes!" they jeered to one another. And no-one in the village could forget the case of the prosperous teacher who hanged himself in the goat shed because he suspected he had the disease. I was told that the *chira* 

<sup>&</sup>lt;sup>73</sup> Fassin (2007: 243-8) makes a similar argument about the international focus on orphans over and above the needs of widowed partners.

which had resulted was so bad that all of the goats had also immediately died, his wives protecting their shame when I met them by telling me that he had died of malaria.

However, in another case I was under the misapprehension for months that Lillian, one of the Community Health Workers, was HIV+ after she told a client, "Just go to the Support Centre, so many people are taking those drugs, even I am taking them," only to discover later that she had lied about her HIV status, in her words, "to make her [client] feel free." This is a more complex pattern of stigma among Luo communities than some have recognised (e.g. Waterman et al. 2007)<sup>74</sup>, and is suggestive of the fact that different stages of the illness are stigmatised more than others, so that being obviously very sick or dying is stigmatised much more than living with HIV, using medication and appearing healthy. Indeed, whilst there was much gossip and speculation which circulated about those who had been very sick but had recently "become fat", these rumours tended to focus upon the changes that had been noted in that person's body, dwelling also upon the various illnesses which had befallen his or her previous partners. However, gossip about "becoming fat" did not include the kind of malicious commentary which was directed at Min Dot. Although stigmatising talk and practice remained common, these embedded enactments of Home-Based Care minimised stigma for certain people at certain times and opened up the possibilities of new kinds of moral practice towards others and oneself in the context of the epidemic.

Through their enactments of Home-Based Care, Community Health Workers clearly delineated the proper content of Home-Based Care as giving advice and objects but *not* providing hands-on care to sick people. They did so in such a way as to avoid unnecessary shame for those suffering from HIV/AIDS related afflictions. Their enactments of policy and disease were thus interlinked, mutually constitutive activities. I will now describe how their enactments were not only embedded in broader contexts of suffering, but also in practices of visiting, receiving guests and knowledge and use of medicines.

### Guests and visits; care and gifts

In the work of Community Health Workers, acts of visiting and spending time with the client were considered to be acts of care in and of themselves. As I described in Chapter One, this is a context where emotions are active, where actions are not expressions of emotions but in important ways *are* those emotions and where active emotions have transformative potential, for good or bad.

<sup>&</sup>lt;sup>74</sup> See also Chapter 5 pg.

Acts of greeting and visiting people were in this sense, emotive gifts. "Thank you for coming" or "Thank you for bringing us a visitor" was not an empty turn of phrase. Home visits were actions of love achieved by bringing attention to the client and by emphasising their value as an individual as well as the strength of relationship between the client and the Community Health Worker. Community Health Workers often found it very difficult to walk past houses of people to whom they were close, but who were not sick. Just as they tried to extend their care to non-HIV+ sick people, they would ask, "Can't we just greet them?" before we entered a house to exchange pleasantries. However, whilst home visits were valued even when nothing material was given, the giving of objects was an important aspect of home visits and something that Community Health Workers aspired to do for their clients. In this section I describe how such giving formed a part of Home-Based Care.

One of the stereotypes with which Luo people are prone to flatter themselves is, "We Luos love guests." It is a stereotype which contains far more than a grain a truth, as anyone who has had the privilege to spend time in Western Kenya will know (cf. Shipton 2007: 75). Reflecting upon this subject, I often heard Luo people quoting versions of Hebrews 13: 2; "Be not forgetful to entertain strangers: for thereby some have entertained angels unawares." Others recounted the Luo fable, the story of Nyagondho son of Ombare, a story that dwells upon the importance of treating one's guests well:

Nyagondho wuod Ombare is a poor man who marries a strange woman who appeared mysteriously out of the lake. She makes him rich in cattle and wives. Then one evening he comes home drunk and quarrels with her, cursing her. She is angry and leaves him, taking all of the wealth with her back into the lake (retold in many places, but see e.g. Bole Odaga 1990).

To have a guest is precious, like a gift or a blessing. Young children and new wives are also referred to as guests [*welo*, sing. *wendo*] in recognition both of the wealth they bring to families and the fact that their membership of families is too often transitory<sup>75</sup>. However, the blessing of a guest also carries obligations which can be hard to sustain, after all as the saying went – *wendo ber gi dichiel* – 'the good guest only visits once' or more literally 'the guest is good the first time'.

<sup>&</sup>lt;sup>75</sup> The under five mortality rate in a region which overlaps Kagot District in 2005 was 227 per 1000 live births, i.e. between 1 in 5 and 1in 4 children could be expected to die before their fifth birthday (Adazu et al. 2005: 1153).

I was often referred to as *wendowa*; 'our guest' and like the Community Health Workers when they visited sick people, my own practice as an anthropologist was situated within the etiquette of visiting and receiving guests. Conventions of receiving guests included a number of key notions. Firstly, a guest should be invited into the home and offered a seat, with wealthy families having large numbers of seats to enable them to accommodate many guests. Just as there was always enough room for another passenger in the *matatus* and buses that plied the roads out of Kagot town, so there was room for another guest and another seat in a Luo home, even though that often meant rushing to another house or homestead to borrow one.

Over many occasions spent preparing food with female friends in Kenya, women of all social classes suggested that when cooking in 'African' homes one should always prepare enough food for the surprise, uninvited (but never unwelcome) visitor. Small requests from travellers and passers-by, for example for drinking water, should never be refused (cf. Shipton 2007: 75). Proper hospitality for important visitors included a meal if they arrived at lunch time or in the evening, ideally of meat (cf.Ocholla-Ayayo 1980: 19). In my experience this was most commonly chicken because of the ease of slaughter and preparation. A guest who arrived mid-morning or afternoon could expect to be served tea or *nyuka* (thin porridge), or if her hosts were wealthy, perhaps soda, with roasted groundnuts or shop-bought bread with margarine.

Not only were certain kinds of behaviour expected of hosts, but guests were also often expected to carry a gift if they went visiting. A visit to in-laws or relations over any distance required the gift of a chicken, or perhaps some food stuff in cheap or plentiful supply at home but harder to come by in the location of the visit. Some visitors might bring a food stuff of which the host was particularly fond such as a specially cooked vegetable dish<sup>76</sup>. Guests were also often given gifts of food to carry home. Again, such gifts were often chickens, eggs or large bags of recently harvested fruits. I was given so many gifts of food during fieldwork that I too began visiting people with bunches of bananas and bags of sugar or eggs which I could leave as gifts. It was with such gifts in my hands that I felt able to justify the continued intrusions I made into people's homes and lives, and with such gifts that my informants continued to welcome me.

While some of these conventions applied only to special kinds of visit and not to everyday visiting between neighbours and kin, I would suggest there was a continuum of practice across these

<sup>&</sup>lt;sup>76</sup> Luo people are famous for their love of dark green vegetables, often very bitter (*kech*), of which they cook many different varieties. Some of these dishes require elaborate preparation over a number of days.

different kinds of visits. A neighbour passing while a family were taking tea or a meal would always be invited to join those eating (although was not obliged to accept, and often did not). The surprise guests who appeared expecting an evening meal had not usually travelled from afar but were neighbours, relatives or men's drinking companions. This everyday sharing and offering of food between homes is particularly helpful as a way of contextualising Community Health Worker caring practices. Like most people in Ramira village, the Community Health Workers had varying degrees of additional, usually fluctuating, forms of income and did not subsist entirely on farming. However, all of them farmed the plots of land around their homes growing staple foods such as maize, millet and sweet potatoes along with a combination of other crops which they used to feed their families and to sell at the market. While there was no sense in which clients were obliged to offer gifts to Community Health Workers, produce from small holdings was frequently exchanged during the quotidian form of visiting in which Community Health Workers and other members of the community engaged. Community Health Workers were often the recipients of such gifts in exchange for their services. The most common gifts was fruit that was in season; perhaps lemons, paw-paw or mangoes.

The Community Health Workers predominantly had clients who lived near their own homes. Sometimes these people were neighbours, in which case they were often relatives or more specifically in-laws, given typical practices of residence and house building in rural Luo areas. On occasion, clients were people who lived in the same compound as the Community Health Worker. One of the Office Girls had two clients, her mother and her sister. Another introduced the daughter of her co-wife as her client. The proximity of their clients and the relationships they had with them meant the women often already had interactions with these people in which gift-giving and sharing of surplus items, especially food, played an important role.

Community Health Workers used their position and access to resources via the organisation to try and provide things to clients. Usually it was medicines or food stuffs that had been donated, but sometimes also school uniforms, blankets and even water storage containers. It was not just that they wished to reciprocate the small gifts of food that they often received from clients, but also to gain status and build relationships through giving (cf. Mauss 1990 [1950]). As Shipton has noted, among Luo people not only is the wife-giver perceived as superior to the wife-taker and the plough team lender to the borrower, but this is a "principle [which] applies to loans of all kinds" (Shipton 1985: 83). He jokingly continues, "It is always much easier for the social scientist to learn about items lent or given away, than about items borrowed or received freely (Ibid.)". Indeed, the common complaint from Community Health Workers that "clients expect you to have something [i.e. to give them] and when you don't have, it brings problems," was as much a complaint about the irregular flow of resources from the organisation as it was of clients' expectations.

Exchanges of food and other items between individuals and homesteads provided a model for the giving of medicines and other items procured through the organisation. Shop-bought medicines existed as objects of value in this community, not only because they had positive transformative potential but literally due to their market value. The gift of medicine was perceived as an act of 'care' because of this inherent value, sometimes regardless of whether the particular medicine given would meet the health needs of the recipient. Lillian and I once visited a young woman whose husband had recently died. Going into the compound we found her standing near an open fire boiling water to cook *kuon*, the local staple food made from ground maize or millet. She stopped her work and invited us inside where she sat down and complained that she had malaria (*awinjo malaria malich*). Lillian gave her client a dose of the anti-malarial that they carried in the kit. Then, although there was clearly not much else wrong with the woman, Lillian continued to rummage through the bag asking me, 'what else can we give her?' looking for more medicine. Eventually she found a bar of soap which satisfied her desire to give something.

Again and again during visits to clients I noted that Community Health Workers tried to find more ways in which they could give things to their clients and more things which they could give. Of course Community Health Workers were interested in the health of their clients. They wanted to aid people's recovery when they were sick and they did primarily use medicine in this way. Yet at the same time, what was being emphasised through the exchange of objects from Community Health Worker to client was primarily the relationship between those two people rather than the health status of the client. Such giving again had the effect of creating a situation in which the exceptionality of HIV was minimised as relationships of care were emphasised.

### Nyamreche and Luo medicine

In *Dholuo*, the term used for Community Health Worker is *nyamrerwa* (pl. *nyamreche*). *Nyamrerwa* is an old term that has been extended to mean Community Health Worker which is also used for women who help others give birth at home; so-called Traditional Birth Attendants. Two of the Community Health Workers, Anne and Purity, were well-known for their experience in delivering babies and told stories of young women knocking at their doors in labour in the middle of the night, although the recent death of a woman in childbirth under the watch of one had badly damaged her reputation as a birth attendant. It seemed to me that these women, who had more Home-Based Care clients than some of the other women, had built new networks of Home-Based clients upon the existing relationships and status that had grown out of their work as birth attendants.

However, others, such as Beatrice and Persila (who had received training in everything from the distribution of contraceptives and community nutrition to public speaking) seemed instead to have gained their status from their association with the organisations which had trained them, and in Beatrice's case, from her own experience of illness. These variances make sense when one considers that the *Dholuo* term *nyamrerwa* refers to a wider concept than that of either midwife or TBA. For example, Kawango Agot writes, "[*Nyamreche*] have multiple roles: traditional midwives, obstetricians, gynaecologists and paediatricians" (1995: 84). Hauge's (1974) description of the *nyamrerua*<sup>77</sup> emphasised knowledge of herbal treatments, particularly around pregnancy, while Ocholla-Ayayo writing at a similar time described the *nyamrerwa* as a specialist in women's and children's illness whose treatments may or may not be linked to magic" (1976: 164).

These broad and overlapping definitions of *nyamreche* fit both with the ambiguities that are inherent in the role of Community Health Worker (see below), and with more general ethnographic observations on Luo medicine. Geissler *et al.* (2002) have argued that Cohen and Odhiambo's (1989: 88-91) claim that Luo people move between various experts as they search for health, including hospitals, private shops and 'local specialists', is a misrepresentation of Luo medicine. In contrast, these authors argue, "Luo medicine is based upon communally shared knowledge, which is held especially by women who take care of children's health, and exchange knowledge of plant remedies around this task" (Ibid.: 41). In this model, medical knowledge is best seen as existing upon a continuum from shared community knowledge to that of well-known experts which passes through the increasing specialisms that women develop through pregnancy, labour and child rearing, particularly in old age (Prince and Geissler 2001). Indeed, washing with and drinking herbal preparations was part of daily life for the majority of people I met in Ramira. Herbs were used both to promote general good health and to deal with particular health problems, as well as ritually for protection against witchcraft. Like other kinds of cooking, it was women who usually made up medicines for the household, although secret powerful medicines to treat *chira* were the province of

<sup>&</sup>lt;sup>77</sup> There is no standardised orthography in *Dholuo*.

ritual experts, often men. The use of herbs was especially common, and often seen as essential, during pregnancy, labour and childrearing, as others have noted (for childrearing see Geissler et al. 2002: 41, for pregnancy see also Moore et al. 2002: 24).

I would further argue that this model provides a useful way of understanding knowledge and use of pharmaceuticals in this community, and the role of pharmaceuticals within Home-Based Care. In general, women in Kagot attended hospitals and clinics far more often than men, to the extent that the nurses at the district hospital would joke, "Women come to the hospital when they are sick, men only come when they are dying!" Just as women's use of herbal preparations increased during pregnancy and child rearing, so these were exactly the occasions when women were most likely to visit hospitals and to be prescribed pharmaceutical medications. While women were most entrenched in the world of institutionalised pharmaceuticals, both men and women availed themselves of the products of the booming private market in pharmaceuticals that exists in this part of Kenya, as it does elsewhere in Africa (van der Geest 1987, Whyte 1991b, Whyte 1992) and indeed world-wide (Whyte et al. 2002).

My informants, both male and female, used and self-prescribed a wide range of pharmaceuticals, especially analgesics and anti-malarials but also some antibiotics, notably Co-trimoxazole, known locally under the brand name Septrin; and Metronidazole, known as Flagyl. These commonly used drugs were exactly those which members of Kagot Development Group considered to appropriately fall within the repertoire of Home-Based Care. Although there were attempts by the Kenyan government and other agencies to *limit* the range of pharmaceuticals that were given by Community Health Workers, those who did Home-Based Care in Kagot were keen to extend as far as possible their access to pharmaceutical medicines that could be given to clients.

Some of the Community Health workers also started up small businesses selling pharmaceuticals. Anne and Purity owned a small pharmacy called the 'Orphans and Widows Self-Help Community Pharmacy', which they operated from a rented shop next to a large hotel on the main road to Kagot. In their pharmacy they sold a range of commonly used medicines, but not the more expensive medicines, medical equipment and antibiotics prescribed at the hospital and stocked by the larger pharmacies in Kagot town. They were trusted by the many customers who frequented their business and Anne was greeted by her clients by the respectful Swahili term '*dacktari*', meaning doctor. Beatrice also started selling a smaller range of medicines from her home while I was doing fieldwork, peddling them when we went to visit clients together and selling from a cloth spread out on the ground at the market near her home where women purchased small items for the evening meal.

The Community Health Workers' involvement in the sale and marketing of pharmaceuticals is demonstrative of the way in which pharmacological knowledge had become integrated into the same kind of knowledge continuum as the herbal medicines referred to by my informants as *yath nyaluo*<sup>78</sup>, literally 'Luo medicine', with Community Health Workers potential specialists at various places on a continuum between the shared knowledge of the whole community and the trained experts at the local hospital or pharmacy.

Such practices can be seen as part of broader changes in the social relations of health care which have taken place as the sale and use of pharmaceuticals have partly moved from what Kleinman (1980) termed the "professional sector" to the "folk sector" (Whyte 1991b, 1992). In the model of Home-Based Care enacted by Community Health Workers pharmaceuticals played a central role and Community Health Workers complained vociferously when there were no drugs available to give to their clients. These attempts by Community Health Workers to use pharmaceuticals to help them develop new relationships with others are practices which not only blur boundaries between supposedly separable spheres of medical practice, but also play upon the distinction between the existence of commonly held knowledge of pharmaceuticals and the women's own knowledge and advantage in terms of access to these resources. They are practices which contain aspects of both an embedded model of care; embedded in broadly shared knowledge of pharmaceuticals and the right to access these benefits to health, and a professionalising model; highlighting the distinctions that Community Health Workers cultivate between themselves and their clients via their access to these drugs.

<sup>&</sup>lt;sup>78</sup> Although more powerful ritual medicines were often spoken of using the Swahili term *manyasi* meaning herbs or grasses.

# **Part Three: Professionalising Enactments**

# Professionalising model



Figure 12. A Wall in Kagot Development Group Office<sup>79</sup>

"I'm Elizabeth Okumu. I'm the chair of Kagot Development Group. Kagot Development Group is a youth group but we don't just stick with youths so we work with people from 0-40 years because we don't want to leave them when they are 35 and because we want to train them to be good people. We were started in 2001 and registered in 2002. Kagot Development Group objective is to advocate and to provide quality health care to PLWHAs [People living with HIV/AIDS] and their families and we started by creating awareness. When we were doing this we saw the importance of taking care of clients at home and these condom issues.

<sup>&</sup>lt;sup>79</sup> Personal information about Community Health Workers has been removed

A mission organisation trained me in HBC [Home-Based Care]. HBC is so many activities as you know, nursing, nutrition, counselling and medication. We try at Kagot Development Group to meet these components because we see many youths are dying. We are doing many things we are doing counselling also home-based care to PLWHAs and orphans and strengthening IGA [Income Generating Activities] among members. We provide recreational facilities to orphans and but the main activities we are doing are Home-Based Care.

Nowadays we think we have achievements. Our collaborators and facilitators at the MoH [Ministry of Health], we talked with them and we saw that the referral [system] was not good but now we are seeing there is a big improvement. Also we when we do trainings and we involve the MoH because they have knowledge and skills. We also collaborate with [an NGO] who used to give us drugs although not so much anymore and they help us with a bicycle for the coordinator. There is the District Development Organisation, we link with them to get more collaborations and we collaborate with agriculture because as you know HBC needs lots of nutrition. We try and encourage the production of foods which are affordable, accessible and available.

We do work with other CBOs [Community-Based Organisations] we are working together and at Kagot Development Group we do refer our clients to our support group to get out in the stigma [*sic*]. Nowadays this is important" (Field notes from my first meeting with Elizabeth Sept. 2006).

My analysis of the practices of Home-Based Care in the previous section described Community Health Workers enacting a version of Home-Based Care as "just the care that people are giving at home" which was embedded in broader forms of care and obligation, and which de-stigmatised aspects of HIV by treating it as "just the disease that is going around". However, at other times these women were engaged in enacting a very different model of Home-Based Care. Elizabeth was the most expert at enacting the professionalising version of Home-Based Care, and it is for this reason that I have begun this section with an extract from the extended speech she gave me when I first met her, and which she gave to all those who visited the organisation. In the professionalising model of care, Home-Based Care was made to exist as an extension of hospital services by being *like* hospital-based care. Stepping into the office of the organisation one immediately noticed that the walls of the room were covered with health information posters about HIV/AIDS and TB and recalled a Kenyan health centre or hospital. Although Elizabeth preached the "affordable, accessible, attainable" mantra, she was particularly keen to use and have under her control desirable medicines and medical objects, which she kept in a locked wooden cupboard which echoed the kinds of cupboards that nurses controlled in the hospital. She moaned about the very limited range of medicines that came in the home care kits produced to new national guidelines which Mildmay and NASCOP provided to the organisation<sup>80</sup>.

Elizabeth would sometimes allow Community Health Workers to take medicines from the office (where she kept them locked up) to give to their clients, but more often she encouraged the referral of clients to her office so that she could "counsel them and see the problems they are having", before giving them medication. She also told Community Health Workers to refer clients who needed to go for testing or treatment to her rather than directly to the District Hospital. Elizabeth's strategies inserted her between the transfer of resources between the Community Health Worker and client as as a key player within their relationship of care, manufacturing an additional level of care between the hospital and the home, as clients visited her on their way to or from the hospital.

When I first met her, Elizabeth agreed that I could 'attach' myself to the organisation to continue my fieldwork. I later regretted settling on the term 'attach' to describe my relationship with the organisation, when I heard her bragging to a male friend, "See how well Kagot Development Group is doing, now I have a student from the University of Nairobi<sup>81</sup> here on attachment!", giving the man the impression that I was being *trained* by Kagot Development Group. While I felt slightly uncomfortable with Elizabeth's attempt to use my presence to give prestige to her organisation and benefit from association with me, such opportunism was a classic feature of the group which was a self-help group in the widest sense of the term. The women who were involved in it used the opportunities it provided not just to access material resources but also to build their status in the local community (cf. Kaler and Cotts-Watkins 2001).

While none of the women received payment for the work that they did for the organisation, there were benefits to their involvement in the group, which were sometimes financial but more often material. For Elizabeth, running the group was a matter of survival. She managed to gather enough

<sup>&</sup>lt;sup>80</sup> The kits were satchel style bags which contained: 1 box of latex gloves; 2 boxes of condoms; a pair of scissors; 3 bars of soap; 60 Paracetamol tablets; 30 multi-vitamin tablets; 30 Piriton tablets; 1 bottle Gentian violet paint; 250ml bottle of bleach; waste disposal bags; 2 rolls of cotton wool; 25 pieces of gauze; 6 rolls of cotton bandages; 20 sachets of oral rehydration salts; 2 tubs of Vaseline; 1 roll of zinc oxide plaster; 2 bottles of antiseptic lotion; two rolls of toilet paper and one packet of nutrition boosting powder (NASCOP and Ministry of Health 2008).

<sup>&</sup>lt;sup>81</sup> I was affiliated to the University of Nairobi research associate during my fieldwork.

funds by being invited to meetings where she was paid a travel or "sitting" allowance to pay rent on a small house on the outskirts of the township supporting her unemployed husband and their six children. It was a precarious existence. Like many middle-class Kenyans, Elizabeth struggled to pay her rent and educate her children, who were regularly sent home from school for non-payment of fees<sup>82</sup>.

The Community Health Workers were often given something when they came to their weekly meetings. Sometimes they received 100 Shillings for 'transport'<sup>83</sup> (although they all walked or came by bicycle). If the organisation had received a food donation, they might be given a large tin of maize or beans or some high protein porridge flour. These gifts of food represented a sizable contribution to the family and in the case of maize for example, might make the basis of three or four meals for a family of 6-8 people<sup>84</sup>. On occasion there would be enough for them to take back for their clients as well as for themselves. Access to medicine was a valued benefit of being in the group because medicines were objects which could usually only be obtained if one had money. After meetings the women would often queue up to ask for medicine from Elizabeth. Finally, a rare but highly valued benefit was being invited to a training course. Trainings were valued highly not only because of the opportunity to learn new things but also because there was always plenty of food and participants were usually paid travel costs and sometimes an additional "sitting allowance" (cf. Swidler and Watkins 2009). Women would wake up early and walk to attend the courses to save as much money as they could. "Sometimes you can get even 500 Shillings a day, and with that you can really do something," Beatrice told me.

The legitimacy of the professionalising model of Home-Based Care was based on training. In the office, this training was advertised via certificates and posters placed on the wall for all to see. For the women who attended the Monday meeting, a line was drawn between those who had been trained as Community Health Workers, and those who were "just members of the support group". But there were also other hierarchies in the organisation *among* those who had been trained. For example, the Office Girls were sent to seminars and workshops more frequently than the Community

<sup>&</sup>lt;sup>82</sup> Although state Primary education (5-14 yrs) is free in Kenya, Secondary education is very expensive. State Primary schools are often over-crowded, meaning middle class parents often prefer to use private schools. Meanwhile both public and private schools usually privatise part of the curriculum by offering extra "tuition". The open secret of "tuition" is that core aspects of the curriculum are taught during these extra sessions and that these students who do not attend will not pass their exams.

 $<sup>^{83}</sup>$  About £0.70 at the time of fieldwork.

<sup>&</sup>lt;sup>84</sup> The majority of these items were paid for via small grants from Mildmay international and AMREF (The African Medical Relief Agency).

Health Workers. Meanwhile, when Elizabeth and the Office Girls went on home visits they spoke of it as "going to the field", drawing a line between themselves and the Community Health Workers, who lived "in the field" and therefore could not go to it<sup>85</sup>.

Having started the organisation, Elizabeth was by far the most successful at professionalising her work. She also had other trappings of professionalism at her disposal, including the office with its large desk and sign on the door which read "Counselling in progress, do not enter." She had built up significant rapport with Ministry of Health staff at the District Hospital, who asked her to "represent the community" at meetings, and who referred NGOs and researchers (including myself) to her office. Elizabeth made various attempts to further professionalise the organisation and its activities while I was there. Staff at the hospital commented of Elizabeth, "Ay! Elizabeth Okumu has become famous!", when I told them that I had now moved my research from the hospital to "the community" and that I would be working with her group.

Where Elizabeth's attempts to become famous were successful, they improved both her own status and wealth and improved the group's chances of accessing funds and goods which would benefit all of its members, in classic patron-client fashion<sup>86</sup>. The most important ways that the group became 'famous' was by being seen to be providing things to their members and clients; by being invited to and attending meetings and seminars; and by building a strong relationship with the Ministry of Health, especially through the District and Divisional Home-Based Care co-ordinators. In the professionalising model of care, what was emphasised about Home-Based Care was its similarity and links to clinical medicine. In this model of Home-Based Care, Community Health Workers needed to be different from others in 'the community' and therefore able to help them.

#### **Uniforms**

In a further attempt at professionalisation, Elizabeth, Philomena and the Community Health Workers made uniforms which could be worn to demonstrate their membership of Kagot Development Group. Uniforms are highly desired items for people within a range of social groups across this part of Kenya, including community groups, colleges, orphanages, churches and other groups such as clubs for young people. Uniforms are the province of school children (representing a considerable outlay and

 $<sup>^{85}</sup>$  Gupta and Ferguson (1997b) have argued that the notion of the field and fieldwork in anthropology often draws upon similar metaphorical distinctions which oppose the field to "civilised places that have lost their connection with nature" (Ibid.: 8).

<sup>&</sup>lt;sup>86</sup> See Chapter 1.

therefore a valued possession for most Kenyan families) as well as certain respected professionals, including nurses, soldiers, police and clergy. Uniforms are valued because they symbolise education and improvement and for their associations with the middle-class professions.

Uniforms in Western Kenya are also a means of empowerment because they have the capacity to symbolise many different things simultaneously. Uniforms are adopted by a wide range of groups, especially of women, whose wearers draw on the ambiguity of their symbolism to promote multiple ends. This is true, for example, of a number of independent Luo churches, the most famous being the Legio Maria whose adherents wear brightly coloured gowns sewn in the style of religious robes. Many other churches have their own uniforms, including the Roho church, whose members wear uniforms which consist of a white dress and hat with a red cross stitched on the front, drawing on both medical and Christian symbolism, making it hard to tell, from a distance, if the women are nurses or nuns. Roho uniforms thus play on the association of these two professions and the correlations between healing, medicine and faith which are central to the Roho faith (Hoehler-Fatton 1996). Comparably, in Mozambique *anereri* prophet healers wear similarly ambiguous uniforms (Luedke 2003: 8) and in the Zion church in South Africa, Comaroff describes members' uniforms as, "Evoking elements emblematic of indigenous and colonial culture, only to revaluate them in their iconoclastic juxtaposition with others" (Comaroff 1985: 224).

Elizabeth was overjoyed when she managed to raise some money to have uniforms made for the group. The Community Health Workers were also very excited at the prospect of owning uniforms and agreed to each make a small contribution towards the costs of making them. The making of the uniforms was a drawn-out affair, which took not only a lot of time, but was the subject of ongoing interest of all those in the group. First, Philomena travelled to Kisumu to find appropriate fabric for the uniforms and returned with a whole roll of a medium weight lilac cotton material which sat in the corner of the office where the Community Health Workers rubbed it between their fingers and commented to one another on its texture and colour. Then they had to find a tailor. Eventually Elizabeth settled on a young deaf woman who was a recent graduate from a nearby school for the deaf. Drawing upon the ambiguous symbolism of the uniform in her attempts to professionalise the group, Elizabeth chose a design for the uniforms which echoed those worn by the nurses and subordinate staff at the local hospital.

Once the uniforms had been made, the women proudly wore them to special meetings at the headquarters of their organisation, particularly when they were welcoming visitors. However, there

were important boundaries around sites where professionalisation was possible. Most interesting, was the fact that uniforms were *never* worn for the regular visits that Community Health Workers made to sick people at home. Although the women were keen to advertise their membership of Kagot Development Group, wearing uniforms did not fit with the kind of embedded care that they provided in the village. Instead they wore their uniforms only on occasions where they wanted to promote their position, for example to special meetings, or if they needed to accompany somebody to the district hospital.



Figure 13. The Community Health Workers visit the District Hospital dressed in their uniforms.

# Hellen and her uniform

The uniforms allowed the further enactment of distinction between members of the group. Purity was the chair of the support group and had a position of relative importance among the Community Health Workers. When I first visited clients with her she took me into home after home until I was exhausted from walking through the bush in the hot sun. Some days later, she also accompanied Colletta and me while we visited Colleta's client. Some distance out of the centre of Ramira, where the two women lived, they asked for directions as we approached a homestead. In the home, we

were introduced to a young woman with painful abscess on her chest that was oozing sticky yellow puss.

After the visit we discussed my work plan for the rest of the week. In the work plan, I was due to spend Thursday with Hellen and Friday with Alice, but I wanted to change the arrangements in order to attend a meeting in Kisumu. Purity disappeared to Alice's home, which was nearby, and Colletta and I sat down on the ground on a *leso* which she had spread out for us and waited for Purity to return, eating oranges that we had been given by the father of the home that we had just visited. Presently, Purity came back and told me, "Hellen can't walk with you. Alice will walk with you on Thursday". I thought no more of this, until sometime later I was in the office and I happened to mention this had happened to Susan, one of the Office Girls, who sucked in her breath and responded,

*"Ee*, Purity was bad to tell you that...you know what happened with Hellen, Elizabeth told Hellen that she shouldn't walk with you because she has not been trained as a Community Health Worker and that she should give her client to one of the other people in our organisation. But when I wrote the work plan I just put her name, she really wanted it and you know she is hard-working and she is doing Home-Based Care, it's just that she hasn't been trained but maybe that her client is more free with her than she can be with someone else..."

When Hellen later approached me to discuss the abscess that afflicted the woman whom I had visited with Colletta and Purity, I realised that this young woman was the client who had been "given to one of the other people in our organisation." Hellen tried to re-establish her ownership of the client in the office when she asked to be given cotton wool, gloves and surgical spirit to take to her client to clean her wound, but despite these efforts, Hellen's position within the group was further side-lined when it emerged that she was not to be made an organisational uniform to wear.

When the seamstress attended the Monday meeting and began measuring the Community Health Workers for uniforms that were to be sewn for them, Hellen sat with the *nyamreche* as they stood up one by one to be measured. I could hear her whispering in Dholuo to her neighbour, "Is she even going to make mine?" "*Akia*" (I don't know), came the reply. Hellen finally stood up to have her measurements taken and Susan, the only office representative in the room at the time was compelled to say to her, "For now we are only making uniforms for those people whose names are written on

the wall," referring to the lists of Community Health Workers, partly shown in the earlier photograph. Both Hellen's disappointment and Susan's distaste at having to relay Elizabeth's instructions in this way were palpable in the uncomfortable silence in the room that followed as Susan busied herself filling out a record sheet in an attempt to divert their mutual embarrassment.

# Record-keeping and legibility: "Embedded" and "professionalising" in conflict

During the period of my fieldwork at Kagot Development Group, one of the group's main sources of funding was through the NGO Mildmay, who provided a small grant to support home visits. At the time, Mildmay were keen to improve the way that the Community-Based Organisations they worked with monitored and reported their activities. Mildmay had been working closely with the Ministry of Health and NASCOP to develop a model for best practice in Home-Based Care, later called the "Nyanza model" (Owuor et al. 2006), which could be rolled out across the country. The Nyanza model involved the completion of monthly Community Health Worker diaries, individual patient Home-Care Plans, and monthly tally sheets at the Community Organisation level (Ibid.: 17-18).

Mildmay provided Kagot Development Group with booklets to be kept at the client's home where home visits could be recorded. However as I suggested above, many of the visits that Community Health Workers made to clients were not formal enough to be written down in such a format. Meanwhile, many of the Community Health Workers found it difficult to write in English, and avoided completing the forms at all. The new monthly report sheets for the Community Health Workers were so complex that the Community Health Workers were not able to complete these documents themselves, and at the end of the month the Office Girls would translate the notes that the Community Health Workers books into the new reports<sup>87</sup>.

This new focus on recording combined with my arrival and the writing of the work-plan which, as I have already mentioned, the Community Health Workers drafted in order to organise themselves to show me their work. The report writing and work-plan had the effect of making home visits legible, in Scott's (1998) sense. That is to say, these processes resembled what Scott has identified as a core practice of state-craft. They simplified a range of complex and heterogeneous activities in an attempt

<sup>&</sup>lt;sup>87</sup> Many of the Community Health Workers found it very difficult to read and write in English, but they were especially put off by some of the difficult shorthand in the form, including the medical abbreviation *rx* meaning treatment, and other abbreviations such as OIs (Opportunistic Infections), ARVs (Anti-retrovirals) and OVC (Orphans and Vulnerable Children). When I left the field, Mildmay were considering changing the reporting system to make it easier for Community Health Workers to use.

to make them easier to manipulate and organise. These attempts to make home visits legible were problematic in the context of the flexible, embedded model though which Community Health Workers carried out Home-Based Care.

One particular point of conflict arose where it emerged that more than one Community Health Worker claimed the same client. In the embedded model of Home-Based Care, it made sense that two or more Community Health Workers might have the same client. I have already described how Community Health Workers often had clients with whom they had a pre-existing relationship. In Ramira, where many Community Health Workers lived near to each other, a number of Community Health Workers might claim the kind of close relationship required to support the Home-Based Care of the same client.

The model of Home-Based Care promoted by Mildmay was one where each Community Health Worker had up to five clients who lived near their own home. Such a model compensated for the burden of supporting Home-Based Care by minimising the distances that Community Health Workers walked to clients and placing a limit on the number of clients Community Health Workers should support. However, it was a model which didn't take into account the fact that some Community Health Workers were better at cultivating clients than others (and wanted to build as large a client base as possible). The model also ignored the structural differences between Community Health Workers which determined who was more likely to have clients (rather than the distance a Community Health Worker lived from the client). It imagined a Community where Community Health Workers were dotted intermittently across the landscape rather than clustered in villages like Ramira. Nor could the model imagine that it might benefit a client to have links to more than one Community Health Worker. Rather the model was based upon an economics of care where Community Health Workers were understood as finite resources who must be managed in order to reach as many different clients as possible.

Required to decide whose client was whose, the Community Health Workers divided up clients over whom there were multiple claims. In one instance, at K'Ogolla, (Ogolla's homestead), Beatrice and Purity divided up the clients *within* the homestead between them. Ogolla became Purity's client, the HIV+ child of his late first wife Beatrice's. And of course in the case of Hellen, who had not been formally trained as a Community Health Worker and whose story I told above, her client was removed and "given" to somebody who had received the training.

# The limits of professionalisation: 'Attachment' at the hospital

Soon after the uniforms were made, Elizabeth announced that she had organised "attachment" for the Community Health Workers at Kagot District Hospital. Her plan was for each of the Community Health Workers to gain experience of different hospital sites including the wards, the Patient Support Centre, the TB clinic and the Maternal and Child Health Clinic. One Monday morning in mid-January the Community Health Workers met at the office and Elizabeth led them up through the town to the hospital, each wearing their newly made lilac uniform. At the hospital, Elizabeth commandeered the District AIDS Officer's assistant into giving the Community Health Workers a tour of the hospital.

Elizabeth explained that she wanted the Community Health Workers to come and work in the hospital every day for five weeks "on attachment" in the different sections so that they could "become known in the hospital and get to know the procedures better." This was news to the Community Health Workers. There were murmurs of dissent at the back of the group. Persila was saying, "I have so many problems I don't know if I'll be able to commit to that" and Beatrice was asking how they would get their work done if they had to come to Kagot all the time.

Attachment was a failure. The Community Health Workers were too busy farming in their *shambas* to attend the hospital every day and were not inclined to walk the 10km round trip to Kagot so frequently. They soon stopped showing up at the hospital. But more than this, Elizabeth's *vision* of work experience didn't really work out. It seemed that although she had an idea of the kinds of tasks the Community Health Workers might do in the hospital, this vision was not shared by the Community Health Workers or hospital staff. Neither group knowing how to proceed, the result was an uncomfortable inertia.

In the wards there was not really any work that the Community Health Workers could do. Subordinate staff did the cleaning and cooking, and family members supported the sick (see Chapter 7). The kind of work appropriate for the Community Health Workers was limited to the occasional delivery of a message or file. In addition to this, nurses who were non-Luo speakers were confused when the Community Health Workers were referred to by the Luo term *nyamrerwa*, as they saw themselves (especially in the maternity ward) as being in the business of rectifying the dangerous practices of *nyamrerche* who to their mind used ineffectual herbs and endangered women's lives by encouraging them to give birth at home. Being faced with their medical 'other', dressed up in uniforms and ready to collaborate with them, was too much for some of the nurses, who responded

by ignoring the Community Health Workers. Despite the uniforms, class and cultural differences between the Community Health Workers and the nurses were revealed when these two groups tried to work together.

In the Maternal and Child health clinic there were also difficulties. When I arrived to see how the programme of attachment was going, I found the two Community Health Workers who were attached there at a loss, not knowing what to do, standing and then sitting alone in the corridor while the nurses stood elsewhere chatting. Again, it was not obvious which tasks the Community Health Workers might be able to do. Subordinate staff who worked at the clinic swept the floors in the morning and gave peer counselling and health education talks, scraping a living on the pittance that they received for this work<sup>88</sup>. Furthermore, the Community Health Workers could not read and write well enough to help with record keeping, which in any case was confidential. In the TB clinic I asked the clinician Zemirah what work she planned to give Anne, the Community Health Worker who was there, and she said, "I think she's going to be doing counselling – does she know how to do counselling?" After less than two weeks, the 'attachment' project had fizzled out.

#### Embedded and professionalising make a policy

In her (2002) book Annemarie Mol follows practices that enact different atheroscleroses in a Dutch hospital, as I described in the opening sections of this chapter. Mol's is an ontological argument which I have found helpful in thinking about the ways that Community Health Workers in Kagot enacted a completely different kind of object, a policy. Following Mol, my argument in this chapter has been that Home-Based Care can best be understood via the practices which enact it.

As Community Health Workers, the women who worked with Kagot Development Group participated in the enactment of two quite different Home-Based Cares. On the one hand, they enacted an embedded model of Home-Based Care where they adopted clients through existing relationships and exchanged material objects and drugs within broader networks of exchange. Community Health Workers minimised the exceptionality of HIV/AIDS by extending their care to people who were not HIV+ and by emphasising the relationships between themselves and their clients over and above their client's HIV status.

On the other hand, in the professionalising model of Home-Based Care they emphasised individual distinction, both between themselves and their clients, but also between one another. In this model

<sup>&</sup>lt;sup>88</sup> They received around 50/= per day (about 30p).

of Home-Based Care they emulated the practices of the formal government health sector through uniforms, posters and similar paraphernalia. They also engaged with HIV/AIDS as a disease requiring a whole raft of exceptional interventions including support groups, counselling, nutritional information and so on.

The embedded and professionalising enactments of Home-Based Care distinguished quite clearly how and by whom Home-Based Care should be done. By defining the parameters of Home-Based Care via these enactments, Community Health Workers made Home-Based Care a policy. Such makings are not simply responses to the enactments of more authoritative and powerful groups who write guidance and handbooks for the organisation of Home-Based Care, but are tangible outputs about which people can say, "this is" or "this is not Home-Based Care".

Equivalently, putting policy into writing within charts, diagrams and reports are enactments of Home-Based Care Based Care which makes policy tangible. Community Health Worker enactments of Home-Based Care do not happen in isolation from these kinds of policy enactments. But they are more than mere responses or interpretations. The relationship is perhaps better seen as a dialogic one, as there is movement and conversation between Community-Based Organisations and NGOs (albeit inflected by power differentials). Moreover, those who write policy documents creatively work on policy by learning, shifting, moderating and rethinking the categories and forms through which policies are organised by reflecting upon delivery as an ongoing process (Green 2007). So if there is 'response' or 'interpretation', this takes place in multiple ways. However, I have further argued that by following the practices which enact Home-Based Care we not only see how Home-Based Care is *done*, we also see what it *is*, undoing the layering effect that occurs when we align policy with making, and 'field practices' with doing.

In her study of the practices which enact different atheroscleroses, Mol's argument is that atherosclerosis is multiple but not fragmented (Ibid.: e.g. 55; 84). She goes on to underline the practices that make these different atheroscleroses hang together. Drawing on Marilyn Strathern's (1991: 35) elaboration of the qualities of *Partial Connections,* Mol argues that atherosclerosis "hangs together but not quite as a *whole*. It is more than one but less than many" (Ibid.: 82, 84, emphasis in original).

In the case outlined here then, how do these different Home-Based Cares, 'embedded' and 'professionalising', hang together to make a policy? Firstly, to use Mol's term, they are *distributed*,

they take place largely (but not exclusively) in different sites. Because the practices that enact them largely remain in these sites (for example uniforms are worn in the office and the hospital, but not in people's homes) they don't often come into conflict. In their distribution, these are caring practices which are spatialised. They are spatial practices in the dual sense that they create certain ideas and boundaries around home and the organisational office as domains of care but also because they literally happen in different places.

Like the caring practices on the wards of the hospital which I describe in Chapter Seven, the caring practices of Community Health Workers are spatialised in ways which underline particular kinds of responsibility for the care of the sick by differentiating the needs of the familial body (supported via the embedded model of care) and the medical body (supported by the professionalising model of care). In cases where these enactments are not well distributed, for example during "attachment" at the hospital (where attempts to professionalise Home-Based Care did not sit well with those who truly were professional health workers), the enactments do not hang together well, and the whole project of Home-Based Care looks decidedly problematic.

There is also *translation* between the two sets of practices, such as in the form of the monthly reports that the Office Girls patiently fill out on behalf of the Community Health Workers, literally translating the notes that Community Health Workers make in their notebooks into the technical English of the NGO reports.

Divergent enactments of Home-Based Care are also *co-ordinated;* they are brought together. In particular they are coordinated by the many terms in circulation around Home-Based Care, including the term "Home-Based Care" itself and others such as "living positively" and "adherence" which travel across different domains of practice acting as a "coordinating mechanism" (Ibid.: 117). Co-ordination also happens via the enactments of Home-Based Care in policy documents which also consider both "embedded" and "professionalising" enactments as relevant to Home-Based Care. Whilst policy makers and NGOs do not condone all aspects of the "embedded" model of Home-Based Care. Whilst policy makers and NGOs do not condone all aspects of the "embedded" model of Home-Based Care, such as extending care to people who are not HIV+, policy and NGO documents do coordinate these different Home-Based Cares. They posit Community Health Workers equally as people who act from 'within' and understand the needs of their own community (embedded) and simultaneously as people who can be trained to transfer information and support to others (professionalising).

Finally, I would suggest that the very ambiguity contained within the role of Community Health Worker also helps to maintain the overall coherence of Home-Based Care as a policy. In the context of participation as a methodology for development in Tanzania, Green (forthcoming 2010) has argued that participatory technologies in international development act as what Star and Greisemer (1989) have termed "boundary objects".

Star and Greisemer developed the concept of boundary objects to describe the role that certain objects played within the diverse networks of people involved in the collection, storage and maintenance of specimens for a University Zoology museum in California; allowing people inhabiting different social worlds to interact, communicate and cooperate with one another. In their terms, the existence of boundary objects helps to clarify "the problem of common representation in diverse intersecting social worlds" (Ibid.: 388). Green uses this concept to argue that the institutions of participation provide sites of alignment for the diverse social groups which come together through development, partly because of abstract notions of participation as a moral good around which diverse actors can enlist, but also through methods standardisation which produces concrete objects and acts which can be labelled as participatory. Green (Ibid.) argues that it is this combination of ambiguity and standardisation which has allowed participation to thrive as a development technology. From this perspective, ambiguity appears necessary for successful development projects which by their very nature must work between many different social worlds. I would similarly argue that Community Health Workers act as "boundary objects"; "objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites" (Star and Griesemer 1989: 393).

Star and Greisemer write, "Scientists manage boundary objects via a set of strategies only loosely comparable to those practiced by marginal people" (Ibid.: 412). However, I suggest here that Community Health Workers become objectified and idealised through policy documents and their own practices. They are not simply "marginal people" actively managing their marginality, but are also boundary objects, acted on by both policy makers and themselves as they inhabit several different social worlds simultaneously. Community Health Workers manage their own marginality by enacting Home-Based Care differently at different times and places, even while this marginality; being "a person who has membership in more than one social world" (Ibid.: 411), is exactly what makes Community Health Workers useful from a policy perspective, enabling and empowering them to act in the fuzzy grey area in-between hospital and home. This is precisely the ambiguity which is

represented graphically in Figure11 (pg 81), "A possible home care unit," where Community Health Workers are literally placed in the grey zone between home and hospital. These divergent enactments of Home-Based Care create a policy which is held together both despite and because of its ambiguities.

# Chapter 4. "Home-Based Care is not a new thing"

In the last chapter, I described some of the practices that enact Home-Based Care by following Community Health Workers as they visited sick people at home and came together at their organisational office. Among other things, I suggested that doing Home-Based Care allowed Community Health Workers to invest in and develop existing relational networks, even as it allowed them to enact distinction and difference from others as a particular kind of developed individual.

In this chapter I continue this discussion with the presentation of further ethnographic data collected during fieldwork with Kagot Development Group, which I place alongside secondary sources from NGOs and the Ministry of Health in addition to historical data from the colonial and early post-colonial periods. My argument is that those aspects of Home-Based Care which might be described as 'neo-liberal' need to be examined in the light of older forms of government intervention and organisation of policy in Kenya, if one is to make sense of the hopes, aspirations and motivations of those who do Home-Based Care, and to the meanings that they attribute to it.

In this chapter, I argue that as a tactic of government, in the sense of those who draw on the (2002 [1978]) work of Foucault<sup>89</sup>, that Home-Based Care is in as many ways 'old' as it is 'new'. In many respects, Home-Based Care is a new category which acts as a blanket for a range of activities, some of which are new but many of which are enduring and mirror previous governmental forms. Home-Based Care 'works', I suggest, partly because it allows people to do something that they were already doing and the doing-of-which was already valued. It is through a combination of older associations with new ideas in circulation about the kinds of responses required to deal with HIV/AIDS that doing Home-Based Care becomes legitimate and worth doing.

Moreover, I argue that rather than being symptomatic of the 'withdrawal' of the state (assumed to be a classic feature of neo-liberal reform), doing Home-Based Care allows people, primarily women, to position themselves as political actors with a relationship to the state through a longstanding set of techniques. These observations suggest the need to, at the very least, qualify and contextualise the label 'neo-liberal', when it is applied to policies like Home-Based Care (cf. Molyneux 2008).

<sup>&</sup>lt;sup>89</sup> Here I am particularly thinking of scholars whose work engages with the way similar practices of government are articulated across different versions of the state e.g. (Li 2007, Moore 1999) rather than through a evolutionary unfolding of forms of government as in the original Foucauldian imaginary.

# Introduction: Government and home

Many recent contributions to the anthropology of development, policy and the state have been influenced by Foucault's (2002 [1978]) essay *Governmentality*, (e.g. Li 2007, Shore and Wright 1997, Thomas 1994, Watts 2003). In this essay, Foucault exposed modern government as a tactical project whose purpose is the welfare (in its broadest sense) of population, where government "deals with men [*sic*] in their relations, their links,...with those things that are wealth, resources, means of subsistence,...and so on" (Ibid.: 208-9), through what is often translated as "the conduct of conduct". That is to say, "government is the attempt to shape human conduct by calculated means" (Li 2007: 5), rather than to directly administer all aspects of people's lives.

A key insight of this work is that governmental practices bring certain realms of intervention into existence (see e.g. Mitchell 2002b, Rose 1999, 1999 [1989], Scott 1998). For example, in a recent (2007) ethnography of the practices of development in Indonesia, Tania Murray Li uses the term "rendered technical" to describe the ways in which development initiatives, like the colonial endeavours to improve which preceded them, consist of sets of practices which work to define and make visible domains for intervention. Li argues that practices of rendering technical define suitable domains for development intervention, identify sites for improvement, outline the nature of the problems to be dealt with and anticipate particular kinds of external intervention. Throughout her book she elaborates upon and extends the term "rendered technical", originally borrowed from Nikolas Rose (1999), whom she quotes at length. For example she writes that practices which render technical represent,

"the domain to be governed as an intelligible field with specifiable limits and particular characteristics...defining boundaries, rendering that within them visible, assembling information about that which is included and devising techniques to mobilize the forces and entities thus revealed" (Rose cited in Li 2007: 7).

When Rose suggests that realms such as that of community are governmental, he is not arguing that communities have been taken over to become instruments of control, but rather that,

"in the institution of community, a sector is brought into existence whose vectors and forces can be mobilized, enrolled, deployed in novel programmes and techniques which encourage and harness active practices of self-management and identity construction, of personal ethics and collective allegiances" (Rose 1999: 176).

This is a claim which is validated in recent work on the anthropology of development which shows the rendering of particular versions of concepts such as 'community', and 'local' through development encounters (Pigg 1992, 1997). Influenced by this body of work, the focus of this chapter is the processes by which the domestic/home and the community are "rendered technical" as targets of Home-Based Care.

I begin from the premise that government is not a fixed context, but can be studied as a shifting set of practices and modes of organising, i.e. as a set of *activities*, thus developing the arguments that I made in the last chapter about policy as practice. Moreover, governmentality is a useful analytic frame to consider Home-Based Care because of the way in which it theorises the practices of government as a continuum (Foucault 2002 [1978]: 206-7, Lemke 2001: 201);

"From the perspective of governmentality, government refers to a continuum, which extends from political government right through to forms of self-regulation, namely 'technologies of the self' as Foucault calls them" (Lemke: Ibid.).

From such a viewpoint, we can see how the multiple associations around a policy on AIDS and more recently HIV/AIDS care can extend from the state into the home, hospitals, and management of the self, without drawing upon a model which assumes that such practices are separable into different 'levels'.

In this chapter I draw attention to the fact that the realms of home, the domestic and the community have been understood as appropriate targets of government since the colonial period. Women's groups, one of the preferred ways of implementing Home-Based Care projects, have long been used as what Foucault understood as a 'technology' of government. The historical longevity of public health practices directed at the home and the use of voluntary associations, women's groups and community-based organisations as a means of governmental intervention since the colonial period is widely recognised (e.g. Lewis 2000, Nguyen 2005: 129). However, I suggest that what has generally been lacking is a rich descriptive analysis which compares new policies with what has gone before. The aim of this chapter is to compare the practices and ideas which cohere around Home-Based Care with previous governmental interventions to manage the home and family.

# Home-Based Care as neo-liberal?

The juxtaposition of different material I offer in this chapter shows the durability of many of the ideas and practices of government associated with Home-Based Care. This allows me to contest and contextualise descriptions of Home-Based Care as 'neo-liberal'. Home and Community-Based Care programmes have been labelled as a mechanism through which volunteers do the work of the state at huge personal cost. Such an argument sees the state as "'downloading' the burden of caring...onto communities and households (Ogden et al. 2006: 338)", and as evading responsibility to share the burden of caring for the sick (Rugalema 2000: 543) by making a virtue out of community compassion in a way that hides the toll on individual community members, particularly women (Nnko et al. 2000, Ogden et al. 2006). Others suggest that Home-Based Care policy frameworks for HIV care are attempts to regulate the plethora of unsystematic needs-based initiatives that have sprung up organically from within the non-governmental and community sectors in response to a heavy burden of disease and poor quality medical infrastructure (Ogden et al. 2006: 336-7, WHO 2002: 6).

These perspectives on Home-Based Care sit within a wider literature on the African experience of neo-liberalism and structural adjustment which assumes a clear distinction between pre and poststructural adjustment Africa, where NGOs are seen as moving into the vacant spaces left by the 'rolling back' of the state, if such spaces are filled at all (e.g. Ferguson 2006). The problem with Ferguson's position is not so much that he over-emphasises the degree to which people in rural Africa understood the role of the state as provider of particular services before the introduction of the reforms of structural adjustment. Rather it is that he envisages a pre-neo-liberal (welfare) state as some kind of a norm, or 'proper form' rather than as a contested set of political networks and enactments, themselves the product of the particular historical contingencies (cf. Arendt 1958, Foucault 2002 [1978]). As a result, Ferguson fails to recognise continuations of practice across the two forms of the state which he has identified. Meanwhile, as I suggested in the previous chapter, whilst Home-Based Care initiatives are widely understood to have begun largely in the so-called 'third sector', from the beginning they have been heavily involved with and often worked through the Ministry of Health.

My argument here need not undermine the claim that the cuts in public services which were part of structural adjustment packages in Kenya were detrimental to the health and economic development of people in Kenya. However, I would argue that the label neo-liberal can become vacuous when applied outside of a narrow context of contracting, privatisation and competition and is a reductive

label when applied to the complex matrix of technologies of government which constitute Home-Based Care. Broadly speaking, my argument is that just as early epidemiological attempts to understand HIV/AIDS involved the replication of enduring stereotypes about 'Africans' and their susceptibility to illness (Packard and Epstein 1991), so too international development initiatives for HIV care resemble previous attempts at social improvement both in terms of the practices which enact them and the philosophies underlying them.

# A meeting at Kagot Development Group

It is Monday, meeting day at Kagot Development Group for the women referred to by **Elizabeth** interchangeably as the support group and the *nyamreche*, or Community Health Workers. It is late in the morning before the women arrive. They do not leave home before they have completed a number of chores around the house and the walk from Ramira village takes almost an hour.

When the women have squeezed into the room, placing chairs in every available space until they begin to sit on the floor upon their leso, **Joyce** begins the meeting with a short prayer. The agenda for the meeting includes voting for a 'chair of welfare' and a treasurer. They then discuss obligations to one another when a family member dies. Should they make funeral contributions only for close family? **Purity** reminds the group that there are those (like herself) without a husband or children. Finally, they agree that 150 Shillings each is an appropriate amount<sup>90</sup>. The meeting slows down as the women become hot and tired. **Elizabeth** has said that she wants to talk to them but has not yet arrived in the office.

When **Elizabeth** finally arrives, shining with enthusiasm in her smart suit tailored from a colourful printed fabric known as *kitenge*, her hair salon-straight and smooth, **Joyce**, who has acted as secretary, stands up and reads the minutes to her. **Elizabeth** has four more items to discuss: A new income generating scheme involving making mats from banana leaves, the repayment of a loan which was made to the Community Health Workers<sup>91</sup> and her plans for an outing to visit another Community Group.

Lastly, **Elizabeth** starts talking about the monthly reports that the Community Health Workers have to fill in. She emphasises that the information in the reports will "go up to

 $<sup>^{90}</sup>$  Equivalent to approximately £1.20 at the time of fieldwork, or 2kg of sugar, 1.5kg of beef or two bags of maize flour, i.e. a considerable amount of money for these women.

<sup>&</sup>lt;sup>91</sup> The Community Health Workers had all been given micro loans of 500 Shillings, approx £3.20 at the time of fieldwork. The loans were funded by AMREF.

provincial level" and provide information for NASCOP. They have to fill them in properly and she will take them to the Ministry of Health. The forms are arranged in pairs. The top sheet is for female clients, the bottom one for male. Each A4 sheet has a space for the name of the client, the number of visits that were made in a month and then, in small columns that fill the page, such things as ARV treatment – you tick or write a dash, no blank spaces – adherence counselling, educational support, TB medication, O.I. medication, nutritional support and so on. The Community Health Workers find the reports very difficult to fill in and **Elizabeth** begins a didactic session, 'What is a CHW?' They are silent, **Beatrice** offers '*Nyamrerwa*'.

Elizabeth:	What is an O.I.?
Beatrice: .	O.I. is opportunistic infection.
Elizabeth:	One kind of opportunistic infection is what?
Joyce:	Headache, cough.
Elizabeth:	They are things like chronic diarrhoea, chronic cough, spots and vaginal

discharge. Septrin<sup>92</sup> is taken for OIs. The TB column is asking if they are on TB drugs, if they have it put a tick, if they don't a dash. Now, what is nutrition?

**Elizabeth** turns her head to look at **Beatrice**, who addresses **Pauline** "It is just eating [*en chiem ka chiem*]. If they eat well you can tick it."

**Elizabeth**: what are psychological problems?

Agnetta [slightly mocking]: I'm ready to tell you.

**Elizabeth**: [ignoring **Agnetta**] It is problems [*weche* lit. words, stories] in somebody's head. If you think deeply about something it is psychological.<sup>9394</sup>

As the meeting ends Purity hands out 100 shillings to each one, for 'transport'. The women begin to leave but some of them complain that they are feeling unwell so they take some drugs from the office. Susan, one of the Office Girls, puts on a glove and counts out pills for them. Panadol for Purity's co-wife and Brufen for Agnetta who has a chest pain.<sup>95</sup>

<sup>&</sup>lt;sup>92</sup> Septrin is the most common local brand-name for the anti-biotic co-trimoxazole, used in HIV care as a prophylaxis for certain common opportunistic infections. See also Chapter 5.

<sup>&</sup>lt;sup>93</sup> I have translated this exchange into English but should emphasise that the women all switched between English and Luo. For example in the sentence from Elizabeth where she describes some kinds of opportunistic infections: "gin kaka diep chronic, chronic cough, kaka spots, kaka vaginal discharge".

<sup>&</sup>lt;sup>94</sup> Thinking deeply is not a sign of academic propensity but is thought to be a sign of depression and worrying too much.

<sup>&</sup>lt;sup>95</sup> The money for 'transport' came from Mildmay. The drugs largely came from a smaller NGO working in the region called ICROSS, but also from Home Based Care Kits, also donated by Mildmay. Access to these funds and items was highly valued by the women who attended weekly meetings and a significant factor in their regular attendance. Elizabeth and Philomena spent much of their time writing proposals for small grants to continue such work.

Income generation, funeral contributions, record keeping, health education, loans, income, gloves, pharmaceuticals. Building upon the arguments that I made in the previous chapter, I continue with the slightly provocative position that what is going on in this encounter is Home-Based Care. Furthermore, I argue that Home-Based Care is a legitimate and worth-while activity, here, in Kagot, precisely because it broadly includes all of these activities.

In Chapter 3 I described how the women in this organisation visited sick people at home, persuaded people to go for HIV tests, fetched water, delivered gloves, medicines and high-protein porridge flour and discussed drug adherence – the more conventional imaginings of Home-Based Care. However, I also argued that many of the activities these women classed as Home-Based Care did not take place in special visits to the home, but were embedded in the more informal context of everyday activities such as fetching water or going to market. I also argued that Home-Based Care was enacted through activities such as attending meetings. It is in this broader approach to thinking about Home-Based Care that one can begin to understand why women volunteer their time to do it, and the kinds of meaning and association they draw from it.

It is striking that the broad conceptualisation of Home-Based Care understood by members of Kagot Development Group is also underlined in policy documents. For example, see the enormous range of activities considered by the World Health Organisation to be "Essential elements of Community Home-Based Care":

CATEGORY	SUBCATEGORY
CATEGORI	SUBCATEGORY
Provision of care	Basic physical care; Palliative care; Psychosocial support and
	counseling; Care of affected and infected children
Continuum of care	Accessibility; Continuity of care; Knowledge of community
	resources; Accessing other forms of community care; Community
	coordination; Record-keeping for ill people; Case-finding; Case
	management
Education	Curriculum development; Educational management and curriculum
	delivery; Outreach; Education to reduce stigma; Mass media
	involvement; Evaluation of education
Supplies and Equipment	Location of the CHBC team; Health centre supplies; Management,
	monitoring and record-keeping; Home-based care kits
Staffing	Supervising and coordinating CHBC; Recruitment; Retaining staff
Financing and sustainability	Budget and finance management; Technical support; Community
	funding; Encouraging volunteers; Pooling resources; Out-of-pocket
	payments; Free services
Monitoring and evaluation	Quality assurance; Quality of care indicators; Monitoring and
	supervision; Informal evaluation; Formal evaluation; Flexibility

#### Table 2. Essential elements of CHBC (WHO 2002: 34)

Meanwhile, in a key document on HIV/AIDS policy, the Kenyan Ministry of Health describes the work of Community Health Workers as follows:

"The CHW's role is ever expanding to assist vulnerable families with food production and food security by referring the most vulnerable to emergency food programmes. They also link clients, caregivers and mature orphans with programmes that train or assist in food production. Strong links with microfinance programmes and income generating activities have been established for HBC recipients and families to help clients, caregivers, and guardians of orphans and vulnerable children (OVCs) with economic support. Strong links with health facilities and community-based support programmes have evolved, thus strengthening the 2-way referral system between community home-based care programmes and local health facilities" (Ministry of Health 2005a).

Following Mol (2002), I argued in the last chapter that Home-Based Care is multiple, and that the differing practices which enact Home-Based Care should not be thought of as different versions of the same object but rather as different 'Home-Based Cares' which are made variously to cohere and remain apart through certain techniques and practices. This multiplicity has enabled Home-Based Care to remain a central part of HIV policy despite the huge shifts that have taken place in HIV care since 2005 with the arrival of free anti-retroviral therapy in Kenya, as it allows a change in emphasis towards slightly different enactments of Home-Based Care whilst retaining an overall sense of coherence.

However, Home-Based Care is also multiple in another sense. It is multiple in its relationships to other kinds of health interventions and a corresponding circulation of ideas, associations and metaphors which are (or have been) worked on and brought together through other divergent practices. This multiplicity links those who do Home-Based Care into relationships which extend through time and space, articulating both connectivity and difference as it does so (cf. Law and Mol 2008, Massey 1993). Unpacking this relational multiplicity – which is the object of the next sections of this chapter – helps to explain both the appeal of Home Based Care to those who do it and to suggest that 'neo-liberal' is a reductive way of describing it.

#### Home-Based Care as 'engaged universal'

There can be no doubt that Nyanza Province suffers a combination of high disease burden, especially of HIV/AIDS, and poor health infrastructure. However, to view Home-Based Care as simply a 'local' response to the experience of AIDS misses the point that doing Home-Based Care ties people into global relationships and draws upon continuities of practice from before the time of AIDS. Equally, to suggest that Home-Based Care is imported from outside is to miss a range of more local meanings and associations.

I find the work of Anna Tsing (1993, 2005) useful in thinking through how policies like Home-Based care can make sense and feel 'local' and yet draw upon highly charged moral categories which are in much wider circulation. Many of the ideas in circulation around Home-Based Care are universals in the sense that they are concepts that matter elsewhere and are part of a moral agenda which has moved around the world, which influences the ways in which Home-Based Care is enacted in places such as Kagot. These globally recognised concepts include ideas such as family, love, community and a good death. I do not mean to suggest that these universals are made in 'The West' and then made

meaningful in the local context of Kagot. Rather, I am interested in how such categories come to make certain actions meaningful in a particular place; as "engaged universals" (Tsing: 2005). These are categories which are also meaningful elsewhere and whose elsewhere meanings are not fixed in 'other' places but are mobile, moving variously in their totality, in partiality and through modification and rupture.

Tsing's interest in "how universals work in a practical sense" (Ibid. 7), drives her to use the engaged universal as a way of thinking through the complexities of environmental politics in Indonesia and to consider how knowledge moves, mobilises and is made meaningful. Tsing argues,

"Engaged universals travel across difference and are charged and changed by their travels. Through friction, universals become practically effective...*All* universals are engaged when considered as practical projects accomplished in a heterogeneous world" (Ibid: 8).

# The tangle of ideas

If we try and unravel some of the ideas and associations in circulation around Home-Based Care, which are engaged via enactments of Home-Based Care in particular places, we quickly see how complex, far-reaching and multi-faceted it is. The morally charged ideas which feed into home-based care have both recent and enduring histories. They include, for example, the Primary Health Care principles of the 1978 Alma-Ata declaration. These emphasised the equitable distribution of health services and the importance of the participation of individuals, families and communities in the planning and implementation of their health care. Primary Health Care was arguably part of a radical shift in development during the 1960's and 70's away from large scale projects to a focus on small projects and basic needs (Packard 1997: 111). Linked to this movement, Home-Based Care initiatives are situated in the context of the ongoing popularity of development interventions which require community 'participation' (e.g. Green 2000, Mosse 2005), particularly through schemes which involve the training of lay people to provide services to the community (e.g. Kaler and Cotts-Watkins 2001, Pigg 1997).

Home-Based Care is also influenced by the growth of the hospice movement in Europe and North America and shifting ideas around enabling a 'good' death, often at home. The hospice movement itself was influenced by the experiences of the many gay men who died of AIDS during the 1980's and 90's. It has in turn been seen as the product of a changing relationship to medicine, both as an 'antimodernist' reaction against the limitations of a hospital culture with its myth of medical infallibility (Hockey 1990: 73-4) and simultaneously as a response to a modern conception of the self which emphasises the right of the individual to participate in decisions and retain some control over their treatment (Lawton 2000: 12-3). This movement itself is not isolated from other shifting moral frameworks. Lawton draws parallels between the rise of the hospice movement, the natural childbirth movement and the growing demand for alternative therapies which emphasised the importance of treating the 'whole' body (Ibid.). Home-Based Care in Kenya has also been influenced by responses for dealing with HIV/AIDS developed in Uganda, which predated and were often seen as superior to concurrent Kenyan interventions<sup>96</sup>.

Over and above this, Home-Based Care takes place in a context where HIV/AIDS has come to be understood as a disease which requires specialist interventions, in terms of care, prevention and research, in ways thought to be beyond the skills and/or resources of the national Ministry of Health. In addition, as HIV/AIDS has become positioned as a disease of 'under-development'<sup>97</sup>, it takes a special place in the work of NGOs and other development organisations. Organising a health intervention (Home-Based Care) around a special kind of disease makes sense in these circumstances.

In Kagot, Home-Based Care also grew out of people's preference to die at home rather than in hospital. Hospital deaths are expensive. Although often willing to risk a last attempt at treatment in hospital for those who are very sick, people I met in Kagot often took their patient home if they became convinced that they saw the signs of approaching death. They did so to avoid the costly expense of keeping a body in the mortuary and later hiring a vehicle to transport it home for burial. At home, people also avoided the sometimes harsh and degrading treatment of hospital nurses. Family members, who were required to provide full-time care to patients when in hospital, often found home care a more flexible arrangement around which they could manage other duties.

This tangle of ideas and practices comes together in Kagot in a way which is morally charged through connectivity to other places, many of which are conceptualised as 'developed'<sup>98</sup>. The connectivity

<sup>&</sup>lt;sup>96</sup> The Ugandan organisation TASO developed some of the first Home-Based Care programmes in East Africa. Some of those who were leading Home-Based Care projects in Nyanza who I met in 2000-1 had been sent on training courses to Uganda, then widely seen as having a better developed HIV/AIDS response than Kenya.

<sup>&</sup>lt;sup>97</sup> Elizabeth Pisani writes disparagingly of the construction of HIV/AIDS as development problem, arguing that a focus on AIDS as a disease of poverty and underdevelopment has diverted attention from epidemiological priorities. While at times problematically polemical, Pisani is right to draw attention to shifting funding priorities within international health agencies. (Pisani 2008)

<sup>&</sup>lt;sup>98</sup> The process of recognising oneself as 'underdeveloped' with a relationship of a particular kind to the 'developed' world has been extensively elaborated upon by anthropologists of development. See for example (Gupta 1998, Pigg 1992)

extends to contexts of poor medical services and enduring practices of care within families, particularly experiences of dealing with the hands-on care of the dying body. This engagement is not without paradox as it makes doing Home-Based Care simultaneously a move towards being a modern 'developed' person whilst also an 'appropriate local technology'; "just the care that people are giving at home". The argument I make in the next section is that this particular set of engagements and connections takes place partly via the historical linkages that exist between the practices, ideas and spaces for implementation of Home-Based Care. Care of the sick; income generation; funeral contributions; record keeping; health education; economic stability; biomedicine; nutrition; agriculture – these disparate activities come together so easily within Home-Based Care, I suggest, because they have been placed together previously.

#### Women's groups and health care in historical context

Throughout the colonial era, in Kenya and across Africa, the domestic arena was seen as an appropriate and important site of intervention for colonial governments and missionaries (Hansen 1992). Women were understood as key to domestic development and women's education in the colonial period revolved almost entirely around domestic science and home-craft (Lewis 2000, especially 52-68, Mutongi 2007: 119-21). This kind of education was highly prized by wealthy men seeking modern brides in the 1940's and 1950's who began to pay high sums of bridewealth for educated women (Mutongi 2007: 121-3).

The colonial encounter changed the domestic realm immeasurably. It influenced everything from the shape of homes, which became square rather than round (Comaroff and Comaroff 1992, Mutongi 2007: 59-60), the choice of goods to buy for the home (Mutongi 2007: 77), to whom and how one should be married (Ibid. 135-8), to how many children a woman should have, and where and how she should have them (Boddy 2007 [1998]: 321, Hunt 1999, Thomas 2003).

The training of women and the need to influence behaviour in people's homes became, in 1940's Kenya, the responsibility of Social Welfare officers. Social welfare was understood as central to economic development, and as something that would be achieved "from the bottom up. The official line was that through associations, clubs and committees people could do this for themselves in their own way, receiving 'maximum of inspiration' and 'minimum of oversight'" (Lewis 2000 citing the 1948 memorandum 'Social Welfare in the Colonies': 313). By the 1950's such clubs and associations proliferated and the gendered role of these kinds of groups was cemented in a range of tasks linked

to women and the home. There are some uncanny echoes between the range of items discussed during the women's meeting at Kagot Development Group presented earlier in this chapter and the list of meeting topics suggested by the Department of Community Development for *Maendeleo ya Wanawake* (Swa. Women's Progress/Development) meetings in the 1950's (cited in Wipper 1975: 100):

- 1. bathing a baby
- 2. health and hygiene in the home
- 3. agriculture-rotation of crops
- 4. children's play, training in character building
- 5. clothing-choice of suitable clothes for climate, etc.
- 6. how to build a mud stove (if the women have their own house)
- 7. child welfare
- 8. hygiene and health in the home
- 9. recipes or cooking demonstration
- 10. agriculture-compost and compost pits
- 11. handwork [sic ] or needlework demonstration
- 12. tea party and concert
- 13. talk on current affairs
- 14. literacy classes should be held in addition to the club meeting

The *Manendeleo ya Wanawake* (hereafter MYWO) clubs are the most famous women's groups in Kenya, started by the wives of settlers and government administrators in the early 1950's. Clubs were founded on notions of the importance of volunteerism and a sense of *noblesse oblige* (Wipper 1975a, 1975b), under the auspices of a colonial government which wanted to use the clubs to quash support for the growing anti-colonial movement, as well as improve the lives of women (Aubrey 1997: 47-51). The clubs were initially hugely popular, particularly in Nyanza province, where there were almost 10,000 members by 1954.

In a series of activities which would be echoed by future Home-Based Care initiatives, MYWO organised the training of African assistants whom they envisaged as taking over leadership of the branches<sup>99</sup> (similar to the management of Community Health Workers by "Trainers of Trainers") through initiatives such as the Jeanes school, which also trained peripatetic teachers to provide

<sup>&</sup>lt;sup>99</sup> African women were expected to remain subordinate to the European leaders and there was consternation when these African women 'assistants' voted out the European leadership of MYWO in 1961 (Aubrey 1997: 52-3).

education in rural schools (Lewis 2000). Activities in MYWO clubs included instruction in child-care, cleanliness, health and hygiene, farming and the making of handicrafts for sale (Wipper 1975b).

The argument that post-colonial development thought and intervention is the legacy of a set of practices, structures and ideas which became hegemonic through the colonial period is made eloquently in Lewis' (2000) detailed historical study of administrative thought and the implementation of colonial welfare policy in Kenya from 1925-52. Lewis identifies a broad-reaching legacy of ideas, practices and infrastructure, which include notions of the socialistic nature of 'African' community (where communities by nature function for the good of all) and the preference for self-help as an instrument of intervention, which continue to underpin current imaginations of Home-Based Care. Many of these ideas were exported from the UK through colonial government machinery, in particular via discourses which linked the prosperity of the nation with the work of mothers in raising strong, healthy children (Davin 1978). As Rose has argued in respect of the rise of the private family as a technology of liberal governmental rule;

"The concern for the health and welfare of children in the early twentieth century...sought to utilize 'the family' and the relations within it as a kind of social or socializing machine in order to fulfil various objectives...through the production of mothers who would want hygienic homes and healthy children" (Rose 1999 [1989]).

In the Kenyan context, Lewis argues that these gendered initiatives held an ambiguous and vulnerable position within colonial welfare policy and were based upon insights which were too easily forgotten in the outbreak and aftermath of the Second World War. However, the fact that some aspects of these interventions appear to re-surface in contemporary development projects suggests the enduring nature of the ideas behind them. These ideas notably include the domestic as a site for development intervention and women as both objects and agents of the improvement of the domestic.

#### Community

Much as I argue here about Home-Based Care, Lewis writes that the Social Welfare Programmes which were introduced by the Colonial Office for 1940's Kenya were,

"built on two platforms: the modernized form of state intervention designed to regulate people's lives, and the traditional ways in which the labouring classes had collectively organized themselves...to improve their economic and political status through co-operative societies, social clubs and savings groups" (Ibid. : 75-6).

Likewise, anthropologist Philip Mayer wrote in 1951, "native authorities are much concerned with the question how far traditional institutions and methods can be made to serve the needs of modern development" (cited in Hill 1991: 31).

Home-Based Care sits among a range of activities in Kenya which have built upon the assumptions that community is a force for good which can be exploited to work for the improvement of all, and of the notion that pre-existing associational forms can be harnessed to achieve this. The most famous example in Kenya is that of *harambee*, which has successfully drawn upon ideas of community and the value of self-help in the achievement of development. *'Harambee!'* (*Swa.* Let's pull together), was the rallying cry of Kenyatta's newly independent Kenya. Building on ideals of African traditionalism which emphasised communal labour, *harambee* activities were central to the building of community facilities, especially rural health facilities and schools in the period immediately following independence (Hill 1991, Maxon 1995: 137-8, Thomas 1985: 8). *Harambee* fundraisers continue to be arranged for everything from the payment of hospital bills and school or college fees to the improvement of public buildings<sup>100</sup>.

In the Luo context there is also a long history of rotating labour groups and other types of collective labour set up to benefit both small groups of individuals and the wider community. Shipton (2007: 107-10) writes that the arrangements for agricultural labour known as *rika* and *saga* almost certainly pre-date the colonial era. Although *rika* groups of women (who join together to do hard agricultural work such as weeding) and the larger *saga* larger work parties, seem less common than in the past, their shape continues in new forms of associational activity (Ibid.). Indeed, Shipton sees the cultivation of indebtedness to and from others as a central tenet of Luo sociality, which is in part achieved through involvement in such groups (Ibid.: 2007).

However, these arrangements do not represent an egalitarian communalism even if this is at times idealised in writing on the Luo (e.g. Odinga 1967) but rather underline hierarchies of power and wealth. The practices of *harambee* grew out of a colonial tradition of forced labour as much as indigenous forms of self-help (Hill 1991: 13-48). *Harambee* meetings and financial contributions at

<sup>&</sup>lt;sup>100</sup> Contemporary *Harambee* are much less about emphasising the idea of working together towards making Kenya a better stronger country (as it was in the period after independence), and more about coming together to help an individual or shared community facility.

weddings and funerals emphasise both the egalitarian ethos of Luo people (Shipton 1989: 17) and are simultaneously "competitive donations" (Parkin 1978: 216) which underline political hierarchy, power and responsibility to others as attention is drawn to generous individuals and groups through the public offering of money (Ibid. 213).

Likewise, Luo arrangements for collective labour are sites where hierarchy over others is articulated. For example, the plough teams which form to share their resources will always plough the fields of those who own the plough and cattle before they plough for those who merely assist them in their enterprise, often after the optimum time for ploughing and planting. As Beatrice explained of her son's attempts to earn a living though fishing, "Fishing is good if you have nets, lamps and boats, but if you are just having your hands it is not so good."

#### Women's groups, patron-client politics and the distribution of resources

In this chapter I have suggested that Home-Based Care interventions in Western Kenya build upon multiple associations with previous and co-existing policies. These are equally enduring and recent; local and global. Simultaneously, they produce and allow multiple enactments of Home-Based Care with the effect of making Home-Based Care slippery and broad enough to work for different people.

While the object of intervention (HIV/AIDS) may be a new one, many of the assumptions which underpin Home-Based Care and the methods for implementing it are not new. They are influenced by previous interventions which are embedded in people's memories and have a dynamic history, moving through practices and institutions like MYWO, which continues to operate a branch office in the centre of Kagot town and to which some of the members of Kagot Development Group also belong. Because of this I have argued that the label 'neo-liberal' requires clarification when applied to Home-Based Care, even if Home-Based Care ostensibly exhibits aspects of a neo-liberal philosophy of government.

Additionally, for the women of Kagot Development Group, their involvement in Home-Based Care is not suggestive of a retreat of the state but rather provides them with a space where they can create a relationship with the state. In this space a kind of contract is created consisting of the distribution of resources on the part of the state in exchange for the women's time and effort, and for being drawn into the state's processes of legibility (cf. Scott 1998). Like many people in Kagot, most of the women involved in Kagot Development Group also belonged to a number of other groups. People's interest and involvement in such groups tended to wax and wane depending upon the natural lifespan of the group, the benefits they accrued by being a member of the group, how much time and money they were expected to contribute as a member (sometimes group leaders required people to invest financially before joining), and whether they trusted the leader of the group to deliver promises and not to 'eat' the money which belonged to the group.

Such groups provided a means for people to make strategic connections outside their immediate kin group where relations could sometimes be strained. They offered possibilities of access to resources that remained outside the control of other members of the household. They were also sites of potential education and training (cf. Swidler and Watkins 2009). In Kagot, membership of groups was political as groups evolved into a power base for the individuals who led them. They became a form of 'patron-client politics' in the sense that a good group leader was expected to be able to procure resources for the group and to share them out fairly;

Beatrice and I are walking around Ramira village. We come out onto a path which goes past Persila's compound. Beatrice tells me we really shouldn't pass without going in. Persila would see it badly. So we walk in and find Persila in her house. She invites us in and we sit down. For some time, **Persila** has been asking me to visit as she has something to discuss with me, and I am keen to find out what it is. Thus we sit down and Persila begins, in a conspiratorial tone, "I'll tell you a secret", and goes on to complain about Elizabeth and Philomena. "They don't share the resources of the organisation properly. Elizabeth used to be thin but since starting Kagot Development Group she has become fat but when we go to the office there is nothing. Although they use our names we don't see any of the benefits. There is a saying in Kenya that the wise eat the foolish, Jofuwo gin chiemb jorieko, I tell you Anne, in Kagot Development Group we are the foolish." Persila and Beatrice continue to complain about Elizabeth and talk about starting up their own group, but then Beatrice comments, "But she's not as bad as John Olilo. He called us to his place and said that we would be starting a new group. He took our names and started that group and got money. He bought *pikipiki* [Swa. motorbike] and his wife was wearing nice clothes but we didn't see anything! Now he has been saying that he wants us to start going to meetings again" (Field notes 23rd Feb 2007).

As I discussed above, those who write on the political economy of Kenya identify patron-client politics, where resources are exchanged for political support, as a key motif of the post-colonial Kenyan state (e.g. Berman 1998, Southall 1999, Weinreb 2001a). This is a pattern which repeats in

the micro politics of associational life. There is an expectation that a successful leader will benefit from resources, and it is not considered wrong that a good leader gain more than others. However, they should balance their own benefit with that of the other members of the group. In return, group members are supposed to support leaders and praise them, giving their names, attending meetings and talking well of them.

In this patron-client model, NGO's can stand in for the state and for one another. The number of NGOs in Kenya has grown exponentially over the last twenty years and their influence over government policy and the distribution of resources has similarly increased. According to Kenyan government records, the number of NGOs in Kenya (both international and local/national) rose from 517 in 1980 to 6524 in 2000 (cited in Amutabi 2006: 44). In the second half of the 1980's Moi attempted to bring the NGO sector under greater state control as NGOs controlled a large percentage of the aid budget to Kenya and were also a vociferous champion of the multi-party state (Amutabi 2006: 31). This process culminated in the 1990 legislation which undertook to control and monitor NGOs by regularly checking their accounts and budgets. It also gave the government the power to de-register any NGOs which engaged in political activity. It was a sign of the growing power and influence of the NGO sector *vis-à-vis* the state that they managed to lobby for substantial amendments to this legislation (Ndegwa 1994).

However, while particular NGOs and coalitions of NGOs positioned themselves against the state, NGOs in Kenya were and are frequently state-like. This is true not only in the sense put forward by Ferguson and Gupta (2002), who argue that focusing on NGO activities as practices of governmentality suggests the inadequacy of the term *non*-governmental organisation when one considers the similarity between the techniques and metaphors used by NGOs and the state to intervene in people's lives. In the highly politicised development space of Kenya, where "the alignment of... "development" initiatives is of the highest *political* importance" (Kanyinga 1995: 69, my emphasis), the distinction between the state and particular NGO's is often very blurred, perhaps most notably in the case of MYWO, which practically became a wing of the governing KANU during the Moi era (Aubrey 1997, Fowler 1991: 69).

This process continues with the numerous NGOs started by politicians and their associates to enable them to deliver resources to potential clients, often upon ethnic lines (Kanyinga 1995: 79, Orvis 2003). Moreover, during the 1990's, shifting the burden of certain government services such as curative health care to NGOs became government policy. The government continued to provide support in kind to these same NGOs (Hearn 1998, 2002: 46-9), whilst simultaneously channelling the resources and activities of these NGOs in politically strategic ways, as in the example of the USAID funded mission hospitals in Rift Valley province during the Moi era (Hearn 2002: 49-51). Meanwhile, even 'independent' NGOs often work through the state, using agents of the state as intermediaries to provide introductions into and for monitoring the community-based sector. The outcome is that NGOs are seen to hold resources in a similar way to the state and to behave in broadly similar ways (cf. Ferguson and Gupta 2002). Speaking of the rapid turnover of NGOs in the region Persila reassured me when I suggested that their project might be in jeopardy when it looked like the funding from Mildmay was drying up; "These groups never stay for long, but when they go another one is just there."

The women who worked at Kagot Development Group did not see themselves as doing the work of the state (or NGOs), but as making their work visible to the state so that they might be able to access its resources<sup>101</sup>. They aligned themselves to different groups as these resources fluctuated over time. Consider the following document, a testimony which Beatrice wrote to promote the work of Kagot Development Group:

"I am the one who wants to speak and my name is Beatrice Onyango.

I joined Kagot Development Group support group in the year 2004. I had become sick and they sent me for testing at the Support Centre, Kagot District [Hospital]. They found that I had the AIDS virus. They did a CD4 count test and they found that my CD4 count was  $28^{102}$  so I began to take ARVs. Kagot Development Group has stood very strongly beside me and has helped me find food and school uniforms for my children. Kagot Development Group has given me blankets. They gave fish, they gave maize, they gave beans. Kagot Development Group has helped me so much. I also have children at secondary school who are there under the name of Kagot Development Group. I have been sent on training for Home-Based Care. Nowadays we also look after sick people [*warito jotuo*]. Kagot Development Group is a transparent group, it doesn't hide the things that it has been given to help people. And so I would like to request you to continue giving to the support group so that they can also give help and continue helping sick people and orphaned children who

<sup>&</sup>lt;sup>101</sup> In an inverse, or response to the kind of practices of 'seeing' described by Scott (1998). I have borrowed this idea from Alice Street.

<sup>&</sup>lt;sup>102</sup> The HIV virus destroys CD4 cells so the CD4 count is used see how much damage HIV has done to a person's immune system. A CD4 count is the number of CD4 cells in a cubic millimetre of blood (mm3). In a healthy adult a CD4 count is in the region of 1000.

have been left to support themselves so that we can improve [medo – literally 'increase'] Luo land.

I am Beatrice. KAGOT DEVELOPMENT GROUP GO AHEAD"<sup>103</sup>(Testimony by Beatrice Onyango 2005, emphasis in original).

This is my translation of Beatrice's testimony, which Elizabeth asked her to write during the period I was working with the group. Elizabeth used such testimonials to promote Kagot Development Group and Beatrice has kindly allowed me to reproduce hers here. Beatrice's testimony is a fascinating document which merits detailed reading. It focuses on the gifts given to her by Kagot Development Group transparent. Her testimony is influenced by relationships which are far-reaching in scope – she writes for a donor audience and projects an image of an ideal organisation framed in the concerns of international organisations. Indeed, in some ways her testimony echoes the organisational reports that Kagot Development Group produced for those who provided them with funds.

Yet her carefully crafted performance also echoes the more local traditions of the Luo praise song and praise naming, known as *pakruok* (translated by Ocholla-Ayayo (1976: 45-9) as "virtue boasting"). *Pakruok* is not simply an offer of praise but a kind of dialogue or game which is opened up through the offering of praise and through one which demands response (Amuka 2000). Praise songs emphasise the relationship between two parties as much as the virtue of the person being praised. Typical of such songs is the frequent repetition of the name of the person being praised, in exactly the same way as Beatrice repeats the name Kagot Development Group in her testimony (e.g. Cohen and Atieno Odhiambo 1989: 120-3).

Beatrice's embellishment of facts can also be understood as an exchange for the resources she receives from the organisation and is in this sense is like the tradition of making payments to harpists who, in exchange, boast about their patrons in songs (Ocholla-Ayayo 1976: 45). While most of what Beatrice says is true, including the description of items that Beatrice has received from the organisation, Beatrice does not have children at secondary school. Neither does Beatrice know what her CD4 count is, nor is she taking ARVs. When I asked her why she had written this, Beatrice explained that Elizabeth wanted people who could say these things but that others, who really were

<sup>&</sup>lt;sup>103</sup> Translated from Luo with the exception of the words, 'support group', 'support centre', 'CD4 count', 'ARVs', 'blankets', 'Secondary', 'Home-Based Care', which are all in English, and the final word, *mbele* meaning ahead or in front, which is Swahili.

taking "those drugs", were afraid to speak. And so she had spoken for them. In doing so she was emphasising the value she placed upon her relationship with Kagot Development Group and carrying out the duties of a client who has received help from one's patron.

#### Feminine distinction

In a recent (2009) article on volunteerism in development projects in rural Malawi, Swidler and Watkins argue that involvement in such projects can be seen as a search for distinction, particularly on the part of those who lead such groups, whom, they argue, often aspire to leave the village rather than to live in it (1189-90). While Swidler and Watkins draw attention to the contradictions between the individual aspirations of participants in development projects and the presumed egalitarian reciprocity of 'local communities', the ethnographic evidence here suggests that the search for individual distinction is not necessarily related to wanting to 'leave the village' but part of broader processes of gendered distinction and power and the quest for the appropriation of external resources which takes place *within* villages. Members of Kagot Development Group described their work as caring for the sick, but as I have shown, they cared within complex networks of obligation where caring and procuring medicines and other resources for their clients allowed them to build their status in the wider community.

In Kagot, involvement in women's groups was part of broader attempts to promote individual development and success. Here, projects like building a house with a tin (rather than grass) roof and sending one's children to school and perhaps ultimately to university and even overseas become markers of mastery of the modern world in a context where it is individual agency rather than community collaboration which is seen to demonstrate 'development' (cf. Green 2000). The women who worked as Community Health Workers had come of age during a period of relative prosperity in Kenya. They had watched some of their female contemporaries complete secondary school and gain prestigious jobs as teachers and nurses for the post-colonial state. Although they themselves had not managed such achievements, they used their involvement with groups like Kagot Development Group and churches to attempt to develop similar kinds of distinction. They were not always successful, I might add, recalling Hellen's attempts to become a Community Health Worker (rather than "just a member of the support group") in the last Chapter. But through these groups, women hoped to align themselves with progress, development, education and position themselves within closer reach of the resources of the state and NGOs.

Success for Kenyan women seems necessarily to combine achievements in the domestic sphere (i.e. as mothers) and extra-domestically. As a popular commentator in the *Daily Nation* newspaper put it of Charity Ngilu, a famous Kenyan politician, "Women must rise above being good managers—of the man, the home, the children and all things spicy and sweet—and boldly step out into visionary leadership" (Coleman 2003, citing Lucy Oriang in the Daily Nation). While powerful women do not carry out domestic tasks themselves, as wives and mothers it is their responsibility to manage them effectively. This stratified understanding of women's power is why, when Susan, the young Office Girl, arrived at the Kagot Development Group office one morning and asked one of the Community Health Workers if the floors had been cleaned that morning, she received the terse reply, "Elizabeth is not an Office Girl!". It is also why descriptions of Ngilu's political career always emphasise that she is a "mother of three" and why she is respectfully called Mama Ngilu by her supporters (e.g. Ibid.; Mzalendo: Eye on parliament: Charity Ngilu).

One of the reasons why Home-Based Care is so appealing to women like Beatrice is that it offers the demonstration of success in both the domestic and a wider political arena where one can access resources and develop an individual status. This success makes all the difference in terms of the life one can lead. Home-Based Care activities are linked into networks of power, status and resources beyond the purely domestic. But because they are associated with a gendered domestic realm which encompasses, is produced by and aligned with women's responsibilities to care for family members and manage domestic processes, this broad range of activities become classed as 'women's work' and as 'care'. They follow on from colonial attempts to improve the home and the nation via the health of the family and good mothering. It is for these reasons that becoming involved in projects such as Home-Based Care are valuable pursuits for those who gain entry to groups like Kagot Development Group.

#### Conclusion

In this chapter, I have shown how the practices of government which enact Home-Based Care cut across versions of the Kenyan state and are (in)formed by previous and contemporaneous government initiatives as well as enduring assumptions about the categories which simultaneously inform them and are targeted by them, particularly community, the domestic/home and women's distinction.

As Michael Brown has argued of home hospice in North America, Home-Based Care is "a philosophy and policy that spatializes a politics of care" (2003: 837). Home-Based Care draws upon notions of boundaries between public and private space in which home is articulated as outside of politics, as the proper site of the nurturing support of families and especially of women's love and labour. But in Home-Based Care (as in previous attempts to manage the labour of the home) these boundaries are blurred through assumptions of the possibility of the management of the home from within the political realm. It is in this blurred public/private space that Home-Based Care creates possibilities for the articulation of differential status *between* women and the acquisition of resources from the state and NGOs.

Some suggest that this "rendering technical" (Li 2007: 7-8) of community and the home is suggestive of a "new diagram of power" (Rose 1991: 188); that of 'neo-liberalism'. My aim here has been to question the novelty of community as a sector of government and to suggest community has long held the paradoxical position of being both the object of development and the means to achieve it (cf. Rose 1999: 167-73). After all, as I have demonstrated above "Community Development" became a key feature of British colonial administration in Kenya from the 1940's (Lewis 2000; Hill 1991: 23-39). I have suggested that many of the practices and ideologies encompassed within colonial community development are present in Home-Based Care. Moreover, doing Home-Based Care provides the women in Kagot Development Group with a means of developing relationships to the state and its resources.

Although Rose (1999) seems at times to be caught between a sense of the dynamic nature of government and an evolutionary unfolding of rationalities of government, his insights into how rationalities of government such as neo-liberalism come to appear consistent which particular practices and policies are helpful. From Rose's perspective it is not so much that particular policies are, or are not, neo-liberal but rather that as a range of divergent techniques of government are developed, through various *ad hoc* means, they are increasingly compared and come to appear coherent;

"In the course of this process, a certain rationality, call it neo-liberalism, came to provide a way of linking up these various tactics...And once they did so, once a kind of rationality could be extracted from them, made to be translatable with them, it could be redirected towards both them and other things...And such rationalities were then embodied in, or came to infuse, a whole variety of practices and assemblages for regulating economic life" (Rose 1999: 27).

This observation, that broader rationalities of government are created through the apparent coherence and shifting relationships between tactics of government, helps make sense of why it is that Home-Based Care can appear as 'neo-liberal' even while the same 'self-help' discourse which underpins it has been used as a marker of socialist government, for example following independence in neighbouring Tanzania (Holmquist 1984).

I argue that 'neo-liberal' can be a reductive label which obscures the relational multiplicity (through time and space) of policy interventions like Home-Based Care. What I argue here is that from the point of view of the practices which enact policies such as Home-Based Care, the notion that there are discrete, unfolding rationalities of government, such as neo-liberalism, which can be used to define and explain such policies, is problematic. 'New' policies around HIV in Western Kenya care speak to an historical experience of development and interventions of the state and enduring conceptions of individual gendered progress, even as they speak of a relationship to the rest of the world. They do so in ways which are both 'old' and 'new'.

# Chapter 5. The Patient Support Centre: Relations of care in HIV treatment.

# Introduction

In the last two chapters, I discussed Home-Based Care in Kagot as a particular kind of response to HIV/AIDS. I now turn my ethnographic analysis to the newly opened Patient Support Centre at Kagot District Hospital and to the relationships of care which developed around the introduction of HIV therapies including ARVs.

The Patient Support Centre catered for adults who were HIV positive, excluding pregnant women, who were treated within the MCH (Mother and Child Health Clinic), through an intervention known as PMTCT (Prevention of Mother to Child Transmission). PMTCT had recently been expanded to include the fathers of infected children and those at risk of HIV, and was becoming known as 'PMTCT plus'. Meanwhile, there was a TB clinic in the hospital where patients were enrolled on anti-TB therapy, considered to be an aspect of HIV treatment because of the close correlation between HIV/AIDS and TB. Medical staff spoke of as a "joined-up approach" to dealing with the two diseases.

TB patients were offered a diagnostic HIV test and counselled in a small room in the TB clinic. They were referred to the Patient Support Centre for HIV treatment where necessary. Diagnostic HIV tests were also offered to people on the wards who were admitted with conditions suggestive of HIV/AIDS<sup>104</sup>. The Voluntary Counselling and Testing clinic and TB clinic were the most common routes

<sup>&</sup>lt;sup>104</sup> The sensitivities around HIV care and treatment created particular kinds of ethical dilemmas for ethnographic research. Hospital staff and patients at Kagot District Hospital were incredibly welcoming and supportive of my research and allowed me to freely access many different areas of the hospital, answering my many enquiries without obvious restriction. My informants' generosity made it seem all the more necessary for me to develop personal boundaries about what I felt should or should not be available for ethnographic consideration. My decisions were informed in part by what I considered to be local understandings of ethical practice which lay behind a desire to please and accommodate visitors as well as my own sense of ethical practice. My personal conviction was that there were areas of HIV care which it was not right for me to witness. I chose not sit in on HIV testing. In the patient support centre, I carried my research out entirely in the waiting room and the nurses' office and did not sit in on patient appointments with the clinician. The TB clinic was so ramshackle that I declined to do fieldwork in the building at all, given that every conversation between patients and staff in one

into HIV care within the hospital. Large numbers of women were tested for HIV during antenatal care and took home with them two doses of Nevirapine<sup>105</sup>; in syrup form for their new born babies and a dose for themselves, to be taken at the onset of labour. However, only a small percentage of those who tested positive registered for ongoing care, for reasons which I speculate upon below. I begin this chapter by examining individual trajectories of illness and care which led people to access treatment before discussing in detail the care provided in the Patient Support Centre.

## Being brave: Becoming a client

Anecdotal and emerging evidence suggests that the availability of free and accessible HIV care is not in itself enough to encourage people to start and adhere to treatment regimes. There are certainly no simple explanations for care seeking behaviour among the people with whom I did my fieldwork. It is difficult to determine why some people rejected HIV care while others embraced it. Those who attended the support centre were heterogeneous in terms of educational background and socioeconomic status. Perhaps more importantly in terms of their choice to seek HIV treatment, each person I met who had tested HIV positive had their own unique and constantly changing biography of experience around HIV/AIDS. Some had cared for loved ones in the late stages of AIDS and recognised similar patterns of illness in themselves. Others felt healthy and had difficultly imagining their own body as 'diseased', and understood the Patient Support Centre as a site for the care only of those who were very sick.

In this section I discuss narratives which I collected during interviews and conversations with people who had made decisions to utilise HIV services at the District Hospital. In these accounts, I highlight the centrality of availability of information and emotional support in decisions to utilise HIV services at the District Hospital. A frequent theme in the data I collected was that the final decision to go for testing and treatment was taken under the influence of a trusted friend or relative. This person usually provided both information and emotional support which my informants described as giving them the courage that was needed to face their status and to begin taking medication. In such narratives, where the person was usually quite sick before seeking treatment, the trusted friend or

room, which was also a site of HIV testing, could be easily heard through the broken door that adjoined the area where anti-TB drugs were stored and nurses' weighed and registered patients. Instead, I talked to hospital staff and patients about their experiences of HIV care in these sites.

<sup>&</sup>lt;sup>105</sup> An anti-retroviral given to pregnant women and neonates to help prevent the transmission of the HIV virus from mother to child.

family member was instrumental in either persuading the person to seek treatment or in organising testing. Going for an HIV test was understood as an act of bravery. For example, Judith, the bright young woman whom I introduced briefly in Chapter One, had been taking anti-TB drugs for eight months and had lost her husband to TB around one year previously. She described to me how she had been offered an HIV test at the TB clinic and refused it. It was her friend who talked to her about the benefits of testing and going for treatment who finally gave her the courage to face the test;

Hannah: When you went to TB clinic did they ever speak to you about getting an HIV test?

Judith: Yeah, they spoke to me, later. When I had used the drugs for about 8 months when I went they tested me, they found that the TB was not in my blood now. So they stopped me from those drugs. After stopping me from those drugs they started telling me about HIV/AIDS. That's when they talked to me. They talked to me and told me that there were drugs for free and if I was sick they would come and treat me for free. They talked to me but my heart was not ready... I didn't believe that I could go for a test and not be HIV positive. So I was afraid. I was afraid so this friend of mine, my last TB release is when that girl saw me, Awuor, my friend. She just came, I just saw her coming I was in the shamba [Swa. vegetable garden], I was working in the shamba she just came and told me 'How are you?' ... She told me that she was taking those TB drugs too. She started telling me about *nini* [Swa. what?], HIV. She just talked to me. She just talked to me and told me, 'Judith, in this world what people want is children and you've got children. See you have got 3 children?' I told her, 'Yes I have got three children.' 'And they are healthy?', 'Yes they are healthy.' 'So what else is left in life? There is nothing now left in life. Just go for the test and you will know what is making you sick. You will know what is making you sick. Every month you are in bed. Mmm, every month you are in bed. After in being in bed for a whole day, you will sit in the sitting room because now you are almost dying and we guys we will eat meat on your nini...burial day. Now when you are still believing that chira<sup>106</sup> I don't know what. I want you to go to the hospital. I volunteer to see you have gone to the hospital, you get the test. So I went to the hospital, district hospital. I went to the district hospital; I was tested and found I was positive. From there is when I started to go to the Support Centre. (Interview, November 2006).

In Judith's account the knowledge that free treatment was available at the hospital was not enough to persuade her to go for a test because she was afraid of knowing her HIV status. It took her trusted friend to give her the courage to confirm her worst suspicions. On many occasions Judith and I also

<sup>&</sup>lt;sup>106</sup> A serious and potentially deadly disease caused by the breaking of taboos (see Chapter 2).

discussed whether she should take her children for HIV testing. Judith was tormented by the possibility that they, too, might be HIV positive. I tried to reassure Judith that this likelihood was relatively small, given that her two youngest children were now 5 and 7 years old, and in good health. However, the fear of knowing, definitively, was too much for her. When Judith died, a few months after I had left Kenya, she died not knowing for sure the HIV status of her children.

In Dorothy's story, she is living at her maternal home following the death of her husband. She is seriously sick and pregnant. The arrival and intervention of her better educated sister is the instrumental force in encouraging her to go for testing and treatment. Like Judith, she speaks of the process of overcoming the deep-seated fear of finding out her HIV status;

"Now, my elder sister came to our home and took me with her to Nairobi. When we reached Nairobi at that time she was working with HIV people. She started counselling me at home. She told me that she wanted to send me for testing. She said that she wanted to send me for HIV testing. I told her, 'I'm afraid'. I was totally afraid. I told her, 'I don't have HIV. Why do you want me to go? What does HIV look like?' She told me, 'You just go,' but I still refused. She took me to another doctor and I was sent to a room and I found there were lots of women there and they were all pregnant. They counselled us there. I made my mind up. I went [for testing]. After testing I left that room and they sent me to another room where I was alone with the doctor. The doctor told me, 'we have found that you have HIV'. I was shocked...from that day I started taking Septrin<sup>107</sup> and multivitamin." (Interview, November 2006, translated from Swahili).

These networks of support were dynamic and as people came to terms with their own sickness, they might also in turn help others by using the knowledge and confidence that they had gained from their own experience with HIV treatment. Sometime later I was at Judith's home again and we were drinking *nyuka*, a thin porridge, together in her mother-in-law's house when a woman came in and greeted us. She was carrying a small basket and was on her way to market. After she left, Judith told me,

The arrival of new kinds of medication and support for HIV in Kagot was instrumental for some of my informants in registering for HIV care at the hospital. Some described the desperate wait for

<sup>&</sup>quot;She is also positive, her husband died. I'm the one who talked to her to go for the test. I saw that she was having this herpes so I talked to her and she went and now she is getting treatment."

<sup>&</sup>lt;sup>107</sup> Co-trimoxazole.

affordable life-saving ARVs to arrive in the local hospital and started treatment as soon as they became available. However, others who were aware of their status needed a second external intervention to persuade them to seek treatment, highlighting again the importance of the 'influential other' in decisions about care seeking and testing and suggesting a more complex set of causes around decisions access to treatment than the simple availability of treatment. Gladys described how an accident with a condom led her to seek advice from a medically qualified friend and how this led her to become registered for treatment;

"This man [I met] insisted I had to go out with him. I told him about my status and he did not mind. So I went out with him and there in the process we were using a condom and that condom busted. Then I had to call my doctor... Since I was having his contact I was to call him. So I called him at night and I explained to him everything. So he directed me to Busia District Hospital. And when we went to Busia District Hospital ... we were told to go to Kisumu [for post exposure prophylaxis]. But first they insisted that we should go for a HIV test. Which we did and the man turned out to be negative. I was reactive. Then I was registered there and since that day I have been going to Busia to collect the drugs. Until late last year when I was very ill I asked for a transfer to the nearest hospital."

The quest for therapy here is not determined by the decisions taken by a "therapy managing group" on behalf of the patient, who is required to follow the patient role by surrendering the right to individual decision making, as Janzen described in his classic (1978) study of Bakongo healing in the former Zaire. On the contrary, these ethnographic examples speak of a drawn-out process of individual decision making influenced by the emotional support of relevant others across different domains of care. This is a process of care seeking which is unlike that which takes place at other stages of people's illness biographies in Kagot, most notably as in the case of hospital admission, where many members of a person's family must come together to support and organise care for the sick person because of the burden upon families entailed by admission (see Chapter 7). Instead, this is a kind of care which relies instead on persuasion by friends and significant others, and upon the final decision of the individual who suspects that they might be sick.

As practices of care these descriptions point to a growing network of support in the wider community around Kagot based upon people sharing their own biographies of experience around AIDS and their knowledge about the disease and its treatment with others. As I suggested earlier, such practices are suggestive of more complex understandings of stigma of HIV in Luo communities than one which focuses upon the relationship between HIV transmission and problematic sexuality (e.g. Waterman et al. 2007). These processes instead underline the existence of networks of care and support and the management of fear of death and uncertainty over time (cf. Whyte 1997, 2002).

As Whyte has argued for Eastern Uganda, HIV/AIDS is not stigmatised only for how it is spread nor for what Robbins (2004: 662) describes as its "troubling genealogy"; "the stigma of its early associations with homosexuals, bisexuals, blacks, sex workers and drug users [which] has continued to stick". For people in Kagot, HIV/AIDS is also stigmatised because of its prognosis. It is the fear of knowing that one will die an untimely and painful death and likely go through the pain and suffering that one's husband, sister or friend went through during months of being sick and bedridden. It is fear of losing control of bodily functions, of becoming unable to support one's own children. This is what people refer to when they speak of being afraid of knowing their status<sup>108</sup>. In Whyte's (1997: 215) terms; "Uncertainty is sometimes preferable to a certainty that is too painful".

These relations of care and support are the beginnings of clinical HIV care. They straddle both the domestic and medical domains by taking information and experience gained within the hospital and using it to persuade other people to move from the home to the hospital for their care. The fact that hospital-based care begins at home for so many people sheds light on why it might be that so many women are willing to test for HIV during pregnancy but decline to begin making the monthly visits which comprise ongoing HIV care.

Like the Ugandan women interviewed by Pool et al. (2001), pregnant women in Kagot often feared what might happen if the knowledge about their HIV status went back to their families. Women attending ante-natal clinics were most often younger women, first or second time mothers, likely to be recently married into their husbands' families and often living within a situation of relative powerlessness. One young women sat anxiously in the PMTCT office with her maternity book<sup>109</sup> concerned by the statement "serology: reactive" within a list of other information relevant for her antenatal care. "My mother-in-law is educated," she worried. "She will understand what this means." She was not happy until the entire page had been torn from the book and the information transcribed without this detail.

<sup>&</sup>lt;sup>108</sup> During fieldwork a local community group organised an HIV/AIDS testing campaign under the banner "Be brave, know your status".

<sup>&</sup>lt;sup>109</sup> Like in other out-patient departments within the hospital, women in ante-natal clinics purchase small exercise books in which clinicians and nurses could write test results etc.

Although it was difficult to get information about why these women chose not to return to hospital for ongoing care (precisely because they did not come back), I surmise that the difference between beginning HIV care in hospital and beginning it at home is specifically the existence (or not) of a supportive relationship within which one can discuss ones hopes and fears and share experiences of care, and through which one can begin the process of disclosure to family members.

Despite the centrality of confidentiality in Kenyan HIV testing and care policies (e.g. Ministry of Health et al. 2001), the reality of daily life in Kagot is that only those who are rich can afford the luxury of choosing whether or not to disclose their status if they wish to access treatment. Wealthy people can travel to distant clinics in Kisumu or other places where they are less likely to meet people whom they know during the course of treatment. Some, like one patient at Kagot District Hospital, can use their connections at the hospital to procure secret appointments with the hospital manager, receiving prescriptions marked "Unknown African Woman". Wealthy people are more likely to be able to cover up their trips to town under the guise of work or business, thus able to deflect the common greetings that meet people whom one finds outside of their homes; *Idhi kanye*? ("Where are you going?"), and *Ia kanye*? (Where are you [coming] from?). Such options are not viable for people who need the support of family members to make the monthly journey to clinic, either to pay for travel, or to organise a lift on the back of a bicycle, or for those whose absence from home must be explained to others.

#### Biological citizenship and relations of care

"Those with cancer or AIDS talk and write about their personal journeys from victimhood to survival. It is as if, at least in part, one is seeing a reversal of the old problematic of stigma, in which one's hidden injury becomes the ground for a claim of valued identity" (Rose 1999 [1989]: 268).

In a number of recent articles, Steven Robins (2004, 2006, 2009) has reflected upon new forms of health citizenship that have developed in South Africa following the growth of pressure groups such as the Treatment Action Campaign (TAC) concerned with expanding rights to access HIV treatment and the creation of collective understandings of biological identity arising from HIV status. Robins writes in the context of a range of literature which has drawn upon Rabinow's (1992) insight that growing scientific knowledge of genetics and biology would result in a new kind of identity politics around biological difference that he termed "biosociality".

For example, Petryna (2002) developed the concept of "biological citizenship" as a way of exploring a set of demands for social welfare based upon particular kinds of biological identity which were forged at the intersection of the economic, legal and scientific contexts which characterised post-socialist, post-Chernobyl Ukraine. Elsewhere, in the context of HIV treatment, Nguyen (2005: 142) speaks of "therapeutic citizenship" as the "dialectic between a global therapeutic economy, local tactics for mobilizing resources, and the biopolitical processes through which humanitarian interventions produce particular subjectivities".

Unlike the well-documented South African (Comaroff 2007, Fassin 2007, Robins 2004) and Brazilian (Biehl 2004, 2007) cases, the arrival of ARVs in Kagot was not linked to a wide-spread activist movement which has developed alongside new concepts of rights-based health citizenship. On the contrary, the arrival of ARVs was understood by most people to be the result of donor generosity and the external acts of outside agencies assumed to exist in a realm outside of the influence of mere mortals. There is, of course, a vibrant NGO and activist sector in Kenya, but these groups tend to be middle or upper-class organisations based in large metropolises. Moreover, the activities of such groups are not linked, in the minds of most people in Kagot, to the availability of new HIV therapies. In Kagot, the arrival of ARVs is instead understood to have developed following the benevolent acts of international donors after a long period of "waiting and praying that one day those drugs might be here", as one of my informants put it.

Where debates on biological and therapeutic citizenship are useful in thinking through the promotion of new kinds of subjectivities in the context of the rollout of HIV therapies in Western Kenya is in the way they draw attention to the particular kinds of difference which become ascribed through shared biological status, such as being HIV+. Staff at the Patient Support Centre in Kagot engaged in practices of care which aimed to specifically influence clients' subjectivity by teaching people how to become a particular kind of client. Clients were trained to adhere to treatment, practice safe sex and avoid pregnancy, attend clinic regularly, eat a balanced diet and disclose their status to significant others. These practices, glossed by some as "living positively", were clearly attempts to shape new kinds of bio-social identity in the context of global programmatics and guidelines for HIV care. However, the lack of an activist culture in Kagot meant that these developments of new kinds of biological subjectivities did not take place alongside radical shifts in enactments of citizenship. The 'right' to HIV treatment was not so much understood through a rights-based understanding of health entitlement as it was upon longstanding relational concepts of the flow of resources out of the state/NGOs to individuals through patron-client models of resource transfer (see Chapter 1).

My argument above was that becoming a client at the support centre generally necessitated both becoming a particular kind of (brave) person and the existence of certain relationships of care and experience. Writing about new subjectivities formed by activism, HIV and its treatment processes in South Africa, Robins has argued that these new subjectivities "are not simply the product of liberal modernist discourses on the rights-bearing citizen. Instead, they are [also] forged in course of the traumatic journeys from 'near death' and 'bare life' to 'new life'" (Robins 2006).

Robins' analysis draws attention to the fact that 'positive' subjectivities and biographies are produced over time as an ongoing process, of which becoming ill, getting tested and accessing treatment is, for some, only the beginning. In the extract from my field notes below, we can see how one client's "traumatic journey" is ongoing within a dialectic of relations of care which include hospital staff; friends and peers and relationships with donors who supply the resources for his treatment as well as with practices that Foucault (1986 [1984]) called "care of the self"<sup>110</sup>.

A man comes out of the clinician's room with his file to collect his drugs. He is well dressed and looks healthy.

**Sister Ogaro**: [To **Samuel**, the social worker] This is one of our best patients in terms of adherence. In fact he has really improved.

**Client**: In fact I am really improved, [I was so thin that] even my shoes were falling off when I first came here. My CD4 was 12 and now it's 117 and I think next time it could even be 200. But you find other friends are there who forget the time [that they should take the drugs], and others fear stigma. I have one friend who is a real candidate for here but he will not come.

He takes his drugs and leaves saying, "Tell the donors *tumeshukuru sana* [Swa. we are very grateful]"

<sup>&</sup>lt;sup>110</sup>Foucault suggested that the management of the self through activities such as eating well, looking after the body, and concern with the environment in which one lived became central to the *logos* of medicine during the Roman era, developing into a contemporary "art of existence dominated by self-preoccupation" (Ibid.: 238), evidencing in this man's monitoring of his weight and CD4 count.

My argument in this chapter is that "biological" or "therapeutic citizenship" falls short as a way of understanding practices of care in the support centre at Kagot District Hospital. This is not only because as Robins (2009: 32) argues, there is need to recognise that global health initiatives are like other globalising processes in that they "seldom result in the seamless imposition of global epistemologies, assemblages and forms of therapeutic citizenship". Like others who have carried out ethnographic research into the introduction of ARVs in East Africa (Meinert et al. 2009) and those who have more generally considered the usefulness of concepts of biological citizenship within medical anthropology (Gibbon and Whyte 2009, Whyte 2009) I have found that concepts of "biological" and "therapeutic citizenship" fall short in Kagot as tools for understanding people's engagements with new therapies.

Concepts of 'biological citizenship' draw attention to the relationship between the individual and the state (or donors) to the exclusion of other kinds of relations of care and biographies of experience involved in forming 'positive' biosubjectivities. I argue that new practices of HIV care in the Support Centre can best be understood precisely by thinking of them *as* practices of care. That is to say, whilst caring relations within the Support Centre linked people into new kinds of global therapeutic economies and promoted a particular kind of 'positive' biosociality, people's engagements with HIV care in Kagot can only be fully understood by thinking through how people's own illness biographies and attempts to 'live positively' intersected with the assemblage of relationships of care that coalesced around the support centre.

These relationships included those that people built up with 'supportive others' prior to accessing treatment. They also included those made with hospital staff, other clients and with materialities and objects of care, including files, CD4 tests and other techniques as the regular measurement of weight (cf. Meinert et al. 2009). The provision of HIV care in Kagot did not so much provide the space for new forms of biological citizenship as allow the development of new relations of care alongside existing repertoires of caring practice within this complex assemblage of objects and practices.

#### The Patient Support Centre

In Kagot, the VCT (Voluntary Counselling and Testing) clinic and the Patient Support Centre sited within the District Hospital were the most obvious of the new interventions to manage HIV care. They were both housed in old buildings which had been renovated specifically to provide these services. The Patient Support Centre had opened in August 2004, in a disused maternity facility

renovated with funding from the Global AIDS Programme (GAP). It provided ARVs and a small range of medicines to treat opportunistic infections as well as regular supplies of Co-trimoxozole<sup>111</sup> and multi-vitamin tablets, given in an effort to boost patients' resistance to opportunistic infections. When the centre opened, ARVs were offered to limited numbers of patients at a cost of 1,500 Shillings per month<sup>112</sup>. This was gradually reduced to 500 Shillings per month until ARVs were made free in March 2006 following a national government decree. When I began fieldwork in March 2006 the Patient Support Centre had 1861 registered patients of whom 370 were on ARVs, but the numbers rapidly increased during my fieldwork.

The building consisted of four rooms. A large L-shaped room where the nursing and administrative staff worked housed filing cabinets, desks for the nurses and a set of weighing scales. A table in the middle of the room was perpetually covered in files, an appointment diary and a huge box of drugs to be given to clients. There was a side door out of the nurses' room directly into the main hospital compound. Clients<sup>113</sup> were usually restricted from using this entrance, which was used primarily by hospital staff and visitors, and were asked to use another entrance at the front of the building which led straight into a room in the centre of the building used as a waiting area.

Clients in the waiting area sat in order on the wooden benches against three of the walls, shuffling along as each took his or her turn to be seen by the clinician. There were two rooms to the left of the clients' entrance. One was used by the clinician on duty and the other variously for counselling, nutritional therapy and as a meeting and store room. At the back of the building were toilets and a washing area which clients were restricted from using ("because they make too much mess"). The layout of the centre had the general effect of creating physical barriers between clients and the health care providers which mirrored what was in general a hierarchical relationship between the two groups. Clients tended to pause at the door that led from the waiting area to the nurses' area, waiting for permission to move into the nurses' room.

<sup>&</sup>lt;sup>111</sup> Co-trimoxazole is a low cost broad-spectrum antimicrobial agent which has been proven to reduce the incidence of many opportunistic infections in HIV including malaria and diarrheal infections when used as a prophylaxis (WHO 2006). <sup>112</sup> Equivalent to around £12 at the time of fieldwork. This was a prohibitive amount for most people who lived

<sup>&</sup>lt;sup>112</sup> Equivalent to around £12 at the time of fieldwork. This was a prohibitive amount for most people who lived in the areas served by the hospital. For many women I met in Kisumu who had travelled to the city to work as maids in wealthy families 1500/= was equivalent or in excess of their monthly salary. In Kagot town, 1500/= was the amount of rent payable monthly on a two bedroom house of the kind rented by teachers and other government workers. These sums were particularly prohibitive given that they were not required simply for oneoff occasions but had to be found every month (cf. Whyte et al. 2004)

<sup>&</sup>lt;sup>113</sup> Those who accessed services at the Support Centre were called clients, not patients.

Inside the nurses' room the staff who worked at the centre sat on chairs arranged around a large table while clients sat on a wooden bench along the wall waiting to be attended to by the nurses. It was the nurses and support workers<sup>114</sup> at the Patient Support Centre who organised the flow of clients. They did this by writing appointment dates on the on the small cards which clients carried with them every time they came to the clinic, searching for people's files from within the filing cabinets, weighing clients and filling in follow-up forms, registering new patients and providing counselling. For much of the period of fieldwork (until these tasks were transferred to a separate location under the responsibility of a hospital pharmacist), they also counted out Co-trimoxazole and multivitamin tablets by hand into envelopes which formed monthly supplies for patients to take home. They also dispensed ARVs and other medication stocked for treating opportunistic infections<sup>115</sup>.

Patients were managed using a system of files and record sheets, all of which were donated by the American health agencies, CDC<sup>116</sup> and USAID. The record sheets appeared to have been designed to be read by a scanning machine, but no such machine existed in Kagot district. Unlike files used on the hospital wards which were attached to a patient only for the duration of an admission until they were sent to decay in an under-serviced records office, these files remained attached to patients and sometimes moved between hospital sites. If a female client became pregnant she would be sent (with her file) from the Support Centre to the Mother and Child Health Clinic.

Both clients and hospital staff were hugely grateful for the new interventions around HIV care which offered hopes of survival where before there had been none. However new treatment initiatives intersected with shifting materialities of care and various organisational problems. Difficult issues included the lack or erratic presence of particular drugs which often resulted in innovative workarounds designed to manage care in ways which dealt with these perpetual shortages. Other

<sup>&</sup>lt;sup>114</sup> These support workers included at various times: a nurse aide employed as an auxiliary member of staff; a trained social worker; two pharmacy students on attachment at the hospital and an anthropologist (as these were precisely the kinds of activities that I also undertook during participant observation in the clinic). One nurse was attached to the support centre on a full time basis, with a second helping out from time to time and covering for her if she was called away.

<sup>&</sup>lt;sup>115</sup> These medications included treatment for oral thrush; analgesics (paracetomol and brufen); fluconazole (for systemic fungal infections) and antibiotic eye ointment among others. Clients received these medications free of charge, but were also sometimes prescribed other medications which they had to purchase from the hospital pharmacy.

pharmacy. <sup>116</sup> Centers for Disease Control. The organisation managed a large fieldstation just outside Kisumu in collaboration with KEMRI (The Kenyan Medical Research Institute).

problems ranged from national-level corruption involving money for HIV treatment to difficulties in the day to day running of the clinic.

Accusations of high-level corruption had dogged the national AIDS programme more or less since its conception, and at the time of field work the Kenyan government was being asked to account for some Sh720 million<sup>117</sup> meant for AIDS, Tuberculosis and Malaria which had apparently gone missing. It had been warned that failure to do so would put at risk Sh7 billion<sup>118</sup> in new grants from the Global Fund (Daily Nation March 30th 2006). At Kagot District Hospital, in a development that seemed potentially linked to the uncertainty of future funds for ARVs, new patients were not initiated on ARVs during most of March and April 2006 because there were no supplies of 'starter packs'. Continuation drugs had been available without problems, but the initiation packs, which had lower levels of Neverapine, were not available. Since this drug often caused side-effects patients were weaned onto it slowly, taking a 50% dose during the first month of treatment. Long lists of clients who met the criteria to be started on ARVs accumulated at the centre, waiting for the drugs to arrive. The supply of some drugs for opportunistic infections, such as Co-Trimoxazole, was also erratic.

The hospital did not, at this time, have the equipment necessary to measure CD4 counts, although a CD4 machine was donated to the hospital later in the year by the American organisation CDC. This made it difficult for clinicians to perform baseline assessments of people's health and to monitor their improvement. Many clients were told to go to Kisumu, the provincial capital for the test, but could not afford the bus fare, or got to the provincial hospital only to find an obstructive member of staff demanding an extortionate (and fraudulent) fee. Meanwhile, clients were asked to subsidise some aspects of their care financially. This included a 50/= registration fee<sup>119</sup> which was used to provide Jane, who worked as an assistant in the clinic, with a 50/= daily allowance. This money was also used to pay for stationery and photocopying. Moreover, some of the staff who worked at the clinic were somewhat less than 100% committed to their work:

**Sister Ogaro** and **Jane** talk together leaving me momentarily outside of their conversation, then **Jane** says to me, "It's so bad!"

Hannah: What, the lack of starter packs?

<sup>&</sup>lt;sup>117</sup> In the region of  $\pounds 6.4$  million.

 $<sup>^{118}</sup>$  In the region of £60 million.

<sup>&</sup>lt;sup>119</sup> About 30p. Approximately the cost of a kilo of maize, which would provide two or three meals for a family of 6. This fee was removed during the fieldwork period. It was decreed by the government that there should be no 'hidden' costs in HIV care.

Jane: Not just that, you see how the Clinical Officer has gone and there are clients waiting? Hannah: Where? Jane: Imagine we don't know. Hannah: But that's rude! Jane: Imagine it's so rude. I [she stops herself and then continues] no, I just hate him. He doesn't care. You can find him even sitting under a tree when people are here. Hannah: Who is his boss, DASCO [the District AIDS Co-ordinator]? Jane: No, there is another CO [Clinical Officer] who supervises the COs. We have been there many times [to complain] but imagine he is still the same. (Field notes 05/04/2006)

#### **Becoming** jokinda

"[M]edicine was not conceived simply as a technique of intervention... It was also supposed to define, in the form of a corpus of knowledge and rules, a way of living, a reflective mode of relation to oneself, to one's body, to food... Medicine was expected to propose, in the form of regimen, a voluntary and rational structure of conduct" (Foucault 1986 [1984]: 99-100).

Once registered at the support centre, clients were encouraged to develop particular kinds of subjectivity which centre staff imagined would enable them to manage what they sometimes described as the "heavy baggage" of HIV diagnosis and treatment. During a later part of my field work I found that Community Health Workers would stress to those who found attending clinic difficult, or who complained about the way they were treated at the hospital, that the people at the hospital liked *jokinda* (sing. *jakinda*), that is people who struggle, who try hard, who are reliable. Those who achieved this were praised by centre staff:

**Millicent** was a long-standing client who came back into the nurses' room having been to see the clinician one morning. **Jane** told her, 'you need to come for a CD4 count test. We are doing them every Thursday at 8am.' **Millicent** replied, 'OK I'll try, but you know that transport is a problem'. **Jane** changed the return clinic date so that it was also on a Thursday and **Millicent** would only have to attend clinic once in the month rather than twice and handed **Millicent** her drugs. She looked at **Millicent** as she handed her the drugs and smiled saying, 'I don't need to tell you [how to use them], nowadays you are an expert!'

Although the walls of the building were decorated with health education posters, clients at the centre received limited information about their treatment through visual materials. Most of the posters on display were related only in very general terms to HIV/AIDS. There was only one poster that related to the specific workings of the clinic, a hand drawn summary of opening times. There was no specific information pertaining to the medication the clients were given at the clinic, the purpose of measuring a person's CD4 count, or other information that related specifically to the treatment being received by clients in the clinic. A television cupboard high in the corner of the waiting room remained empty throughout the period of my fieldwork despite the availability of a television in the hospital for the purpose of showing educational films to clients while they were waiting to receive treatment. Hospital administrators explained that there had previously been a break-in and that the building was not secure enough to leave a television in overnight, although not all agreed that this was their motivation for keeping the television locked up elsewhere in the hospital.

Many of the people who attended clinic were illiterate, or found it difficult to read in English and Swahili, so were restricted from accessing even the very limited information available in the posters, the majority of which were not written in Luo. Sometimes staff members were given information leaflets which did contain more specific information about HIV testing and treatment, but they did not usually put them out in the waiting area because they complained that when they did this the clients took them home with them.

Meanwhile, although there were certainly gaps in clients' knowledge about HIV care, most clients who attended the support centre were not in the habit of asking questions about their treatment during the normal routines of care that they received. In fact, frequently there were surprisingly few interactions of any kind between staff and clients outside of essential communication needed to facilitate the progress of routines in the centre. Niceties of greeting, both the physical act of shaking hands and verbal greetings, considered an essential opening in almost all interactions with others in daily life outside the support centre, were largely avoided in the routine exchanges between support centre staff and clients. In truth, at times the repetitive routines of care overtook conversation to make silence the norm in interactions between staff and clients;

"Then another woman gives **Belinda** [a pharmacy student on placement at the hospital] her card. They don't talk at all as **Belinda** copies her name onto the follow-up form. **Belinda** just speaks to her to tell her to get on the scales, and she takes her shoes off and steps up" (Field notes 24/04/2006).

This is typical of the many occasions when verbal communication between clients and staff was limited to the giving of orders by the support centre staff. Once they had been weighed, clients like the one above were sent with their files to wait for the clinician. The same person might then come out of her check-up with the clinician and carry her folder back into the nurses' room where one of the nurses would read it and hand her a bag of Septrin and another of multi-vitamin tablets while saying, *"ariyo pile, achiel pile"* (two a day, one a day), at which point the client would leave the support centre without having spoken a word to any of the support centre staff except the clinician.

## Counselling

It was through sessions of didactic training, referred to by staff as 'counselling', that clients received most of their information about HIV care in the hospital. Information was given almost exclusively within fixed sessions; 'enrolment', 'adherence counselling' and 'ongoing counselling'. Counselling in this sense was more or less elided with health education. In the process of enrolment staff asked the new client questions and filled in a form which then became the basis of that client's file. The information which was provided in the form included the client's height and weight, where they had gone for testing and the type of test which had been done, followed by questions relating to the domestic and socio-economic situation of the client. The form functioned as a tool to collect information about the client rather than to induct them into the system of treatment at the support centre and had clearly been designed to meet the needs of researchers rather than clients at the centre.

It was only after filling in the form with the new client that the client was given specific information about the obligations upon them now that they had registered at the Support Centre. The member of staff doing the enrolment would make a card for clinic with a number on it which corresponded to the number on the client's file, and explain that they should bring this card every time they attended. Clients were told they should not miss their clinic date but could attend at any time if they became unwell before their next appointment. The member of staff would also talk about treatment regimes explaining that they provided Septrin and multivitamin tablets to be taken every day to boost immunity. They discussed going for a CD4 count test, to see "whether the virus had gone far ahead" and gave some basic information about ARVs. At this point, staff emphasised that ARVs were a medicine for life, that "once you start them you cannot miss even one dose", and that ARVs have to be taken at exactly the same time every day. Adherence counselling was given in two sessions and its purpose was understood as giving the client the information they needed to start taking ARVs. The requirement of attending the two counselling sessions was also used to establish whether a client was reliable enough to be started on ARVs. During adherence counselling, clients were told again about treatment regimes, and the kind of sideeffects they could expect as well as what to do if they experienced serious side effects. In the second session clients were asked questions to assess whether they had understood this information. Like 'enrolment', 'adherence counselling' was seen primarily as a space in which to give information to clients rather than to respond to clients' concerns or questions.

The final type of counselling provided, described as 'ongoing counselling' was not given to all clients. Some clients who were depressed were referred for counselling by the clinician during their monthly appointment, but more often, 'ongoing counselling' was a single session of counselling that was seen as a means to teach clients about HIV rather than as a way to help clients discuss and deal with problems or to answer their questions about treatment. When a client came in who had missed clinic, or made a comment that showed his ignorance about modes of transmission for example, staff might comment, 'eh, he really needs counselling', before taking the client to the counselling room to talk to him in private.

This kind of counselling as training or teaching can be considered an example of what Rose (1999 [1989]) has termed "psycho-therapeutic procedures", by which he understood a wide-range of practices which includes everything from therapy sessions to self-help books and which extends well beyond psychiatric understandings of mental health to a concern with the governing of subjectivity. For Rose, these technologies of government construct a particular kind of self who becomes key to the management of their own health, a self which is "not merely enabled to choose, but obliged to construct a life in terms of its choices" (Ibid.: 231). Within such practices of "governing the soul", argues Rose, individual behaviours come to be thought of not as projections of an inner self, but as techniques or skills which can be learnt or taught by experts, but which ideally come to be managed by ourselves. In the Patient Support Centre, clients also worked on one another's subjectivities; in an echo of the kinds of support and persuasion that they offered to one another before starting treatment;

In the waiting room there is the sound of bubbling conversation, which I can't make out, but **Jane** [who works in the support centre as a volunteer] says to me, "now the patients are counselling one another, I like it so much."

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Hannah:Yes, it really makes a person feel better, when they feel they are not alone.Jane:Sometimes you see them coming in from VCT like this [she holds her headin her hands].Then someone will say [she touches me on the shoulder] 'Eh! You shouldhave seen me when I first come in, I was dying.Now I'm taking medicine and eating andlook at me now!

**Jane** goes out into the waiting room and talks to the patients joining in their loud conversation. She comes back in saying, 'She is saying that now she is positive she is not going to eat with the children so I told her I am kissing and hugging you and I am negative, do you think I would do that if I could get positive! Eh she really needs counselling! (Field notes 05/04/2006)

## **Defaulters**

Through the process of becoming *jokinda* and through illness biographies which passed from 'near death' and 'bare life' to 'new life', to return to Robin's terms, clients at the Support Centre built up shared understanding of new biosubjectivities, of what it meant to live with HIV. However, the same relations of care which formed in order to help shape clients into this kind of subject could also encourage patients to conform to the routines of the centre by not speaking to nurses and support staff, following their instructions and being acquiescent, as I described above.

Moreover, relations of care sometimes broke down completely because of the difficulties that clients had in becoming *jokinda*, and the fear of reprimand when staff blamed them for their failure to develop this particular kind of subjectivity. The example below shows how centre staff drew on a moralised model of adherence and not only lectured one particular client for non-attendance, but also blamed her and her (bad) behaviour for an infection that had afflicted her and even threatened to restrict the services they provided.

A woman came in who had a scarf tied over the lower part of her face and struggled to talk to centre staff. Clearly the scarf was hiding an infection around her mouth that she was ashamed to let people see. **Jane** began talking to her and discovered that she was registered as a client at the centre but had not attended her clinic appointments for some time. At this point two other women working in the room joined **Jane** to chastise the woman, scolding her for not attending clinic and reminding her that she was supposed to come to clinic every month. The woman stood silently listening to their complaints. **Jane** went to the filing cabinet and then came back to the table and laid the woman's file down saying angrily in English "maybe she's not ready for a file...you see the way her mouth has become septic because she did not get treatment early enough."

Blaming the victim has been identified as "a powerful current in the social experience of AIDS" (Castro and Farmer 2005), where much of contemporary analysis of HIV care, from "cost-effectiveness" to patient "non-compliance," inevitably leads to blaming the victims of the disease. For Farmer, such "geographies of blame" hide the reality of larger structural forces, global as well as local, which determine why some people are sick and others are not. In other words, in the case of this woman, the possible factors that led to her missing clinic; such as poverty, domestic violence, stigma or a misunderstanding of how clinic processes work, are hidden by the discourse of blame that the centre staff engaged in, where her personal failure as a patient is seen as the cause of her infection.

Relations of care also broke down because patients misunderstood the precise nature of the role they were supposed to play in their own treatment:

I visited Rose with a Community Health Worker. We asked her if she was attending the support centre and what medicines she was taking. She pulled out her card for the clinic which showed that she was almost two months late for her appointment. She explained that her appointment day had fallen on 16<sup>th</sup> of the last month and as she had to attend a funeral on that day she was waiting for the 16<sup>th</sup> of the following month to attend again. She thought that she only had one chance in a month to attend clinic and as she had missed her last appointment she was waiting for the following month to attend.

Missing clinic appointments because of funerals was a common occurrence at the Support Centre, and often elicited the following sarcastic response: "She is telling me that she has not been because she was at a funeral, so I am asking if she has been at a funeral all this time". Pushing the blame onto the client, centre employees avoided the issue of whether their own systems of care might be at fault, or indeed their own explanations to clients of what was expected of them. Reprimand for non-adherence was such a commonplace part of caring relations at the support centre that both clients and staff expected it from those whose role was to shape particular kinds of patient subjects:

**Lillian**, a Community Health Worker took me to visit one of her clients, a woman called **Beatrice**. **Beatrice** had previously tested positive and had started treatment at the support centre which was a walk of about 5km from her home. She described how she had recently been sick and confined to her bed, far too sick to walk to the hospital for treatment and as a result had not been to the support centre for the last three months. **Beatrice** agreed to start

going for treatment again but was worried about the reception she would get if she went alone. **Lillian** looked through her hospital book and found a request for a CD4 count assay along with her clinic card. **Beatrice** was worried about going back for treatment on her own and doubted her ability to manage the hospital systems and to get her CD4 count tested, so **Lillian** suggested that we all meet her at the hospital the next morning to accompany her.

I was the first to arrive at the hospital and went to the lab with **Beatrice**<sup>120</sup>. After her blood had been taken we walked down to the support centre together. I handed her card to the support centre staff and chatted to them for a few minutes. When **Beatrice's** file had been taken out of the cabinet I went to tell **Beatrice** that I was leaving, but she stopped me and begged me to go and speak to the staff again to explain to them the situation and ask them to be kind to her, "They are really going to bother me (Swa. *watanisumbua sana*)," she worried. At **Beatrice's** request I went to tell the nurses not to be harsh with her, explaining that the reason she had missed clinic for so long was because she had been sick and could not walk to clinic. The Sister on duty said to me, "It's OK but you need to go and tell the clinician too, or she will be harsh with her when she sees her" (Field notes 13/11/2006).

However, not all kinds of relationship in the Support Centre were based upon these kinds of hierarchical relationships, nor did clients necessarily slip quietly into a smooth-running routine of care. Practices of care were often highly routine, but at times the support centre functioned not through the easy functioning of regulated routine, but more like this:

Suddenly the nurses' room is full of patients again. Some have come for clinic appointments, one wants to know her CD4 test results and others who have had their blood taken put cotton wool swabs into the bin. I notice that some of the bloody swabs fall on the floor. A man comes in, he wants a CD4 test but he is told that he is too late. A woman enters with a toddler who is screaming, he has had his blood taken, being comforted by his mother. A woman says to **Sister Ogaro**, '*an gi penjo*' [I have a question] and wants her test results from last week. **Sister takes** her card. All the patients are standing and it seems like chaos. Everyone wants to talk to **Sister Ogaro** or **Belinda** and is huddling around them. The visiting nurse, **Matilda**, sits down and puts fasteners into files. Meanwhile **Sister Ogaro** can't find the woman's results so she hands her the file with all the CD4 results in it

<sup>&</sup>lt;sup>120</sup> By this time there was a CD4 machine at the hospital laboratory and tests were being undertaken free of charge, although it was still not working reliably due to intermittent shortages of reagents. Also lab staff were finding it hard to carry out the large number of tests being requested and were limiting the number of tests they would carry out.

so that she can search through herself to look for hers and **Belinda** is giving medicine to another woman, explaining in Swahili how to take it. (Field notes 06/04/2006)

Moreover, staff often developed close relationships with clients over time, and went out of their way to help people, especially those who lived a long way from the clinic, like Margaret (above) whose clinic appointments were rearranged to save her time and transport costs, and in the case of this client:

A client hands a prescription for ARVs to Jane but she tells him they do not have any. He asks what the drugs in the corner are and she replies, 'They are continuation packs. Starter packs are not there'.

Jane: [to client] I can't put you on those drugs. [To me]: We don't have starter packs, it's a problem.

Client: So when now do I come back?

Jane: Call me first to see if they have arrived.

He saves Jane's number in his mobile phone. Meanwhile, **Jane** gets a call on her mobile phone, someone [from a local NGO] is offering to bring her Septrin as they have run out. **Jane** tells the client that he should wait for Septrin but he says that he has it in plenty. Then **Jane** notices that he has thrush in his month and asks, 'Did I give you something for that tongue?' **Client**: No. **Jane** gives him something and then he leaves. (Field notes 05/04/2006)

What these examples point to is that relations of care were influenced by assemblages of relations and objects of care, in ways which developed over time. Relationships between clients and staff, sometimes developed into friendship and genuine affection but they were more often hierarchical.

The majority of the clients at the support centre were women ("Mothers have the courage to know", the resident social worker once told me). However, it was notable that men, more often than women, were those who were confident enough to ask questions and to develop more egalitarian relationships with centre staff;

**Michael** was a long-term client who came in asking to get his drugs a few days early as he had to travel to Nairobi that weekend. **Jane** looked at him and joked, 'and we have to send

the drugs to Nairobi by Akamba<sup>121</sup> again...[to me] imagine there was a time he was in Nairobi and he was going to miss so we had to send them via Akamba and I was like ... **Michael**?? After agreeing he could see the clinician the following day, **Michael** got up to go but stood on the scales before he left. 'Good boy, I'm a good boy', he said, 'I'm nearly 85 [kg] again. I used to weigh 85kg.'

In this extract Michael behaves more like a member of staff than a client, standing on the scales and weighing himself rather than waiting for the order to be weighed. Michael is a well-educated professional and engages with the nursing staff as an equal. Most clients carefully took their shoes off before they stood on the scales; many women even removed scarves that they wore on their heads. However, the scales provided staff and few clients like Michael with the opportunity to engage in friendly banter. Here is Olwendo the District AIDS co-ordinator (DASCO) coming to visit the Patient Support Centre:

**Olwendo** steps onto the scale, '**NyaUgenya** [Girl from Ugenya; he refers to **Jane** here], an kilo adi?' [how much do I weigh?], he asks. Jane looks at the scales and tells him, '79'.

**Olwendo**: Eh! 79 is too much. I should be 74-5. Sometimes if I eat a lot of *mandazi* [doughnuts] I can go up to 83...and when you go to seminars a lot you get fat [he gestures fatness by rounding his shoulders and lifting his arms away from his body].

# Conclusion

In this chapter I have described ethnographically how relations of care in the support centre combined with attempts to develop particular kinds of 'positive' subjectivity and shifting illness biographies to shape experiences of HIV care in Kagot. Relations of care included those with significant others at home, hospital staff, other clients, and with material objects of care including files, weighing scales and CD4 counts.

I have argued that these complex, shifting relationships are inflected both by the organisation of care within the Support Centre and by relationships which extend out of the support centre into other domains of social life. Being a client at the Support Centre is an experience punctuated by erratic

<sup>&</sup>lt;sup>121</sup> A bus company. These bus companies not only transport passengers but also provide a reliable parcel and letter service where people can go to the bus station and pick up their packages the day after they have been sent.

flows of resources and the ongoing monitoring of the self by centre staff and by oneself as one struggles to become *jokinda*, and to 'live positively'.

In describing the complex nexus of caring relations which come together around the Patient Support Centre, I do not so much generate new knowledge about HIV care as reiterate the broad point (made variously by others whom I have citied earlier in this Chapter) that when studying new medical technologies we should not lose sight of what medical anthropology has already taught us about the way in which medical care is embedded in broad and complex social networks. In Kagot, it is the context of networks of care that enables understanding of the kinds of new subjectivities which are adopted as people undertake HIV treatment, rather than a growing sense of rights-based health citizenship where the right which is emphasised is the right to 'life itself' (Comaroff 2007) via the provision of medicines. Centre staff encouraged clients to develop particular kinds of 'positive' biosociality and to become *jokinda*, but it is only within the context of broader relations of care in which living with these 'positive' subjectivities can be understood.

# Chapter 6. Fear/respect and medical care

In this chapter and the one which follows, I describe in more detail how hospital is enacted as a domain of care by considering this as a process which happens in relation, and in contrast to home. The arguments I make over the next two chapters are, at first sight, quite different. In this chapter I build upon the discussion that I began to open up in the previous chapter on HIV care in the Support Centre about the place of hierarchy between staff and clients within their relationships of care. I use the most extreme form of hierarchical care which I witnessed within the hospital, that of the labour room, as a way into this discussion, and make the argument that relations of care within the hospital between medical staff and patients can be thought of as social practices which resemble caring practices within familial relationships. My argument goes further than my claim in the last chapter that clinical care often begins within particular kinds of relationship at home or among friends. Rather than familial and medical care existing as contrasting and opposing kinds of care, or as different sites of care within complex illness biographies, my argument here is that caring relationships at home provided a set of models for the practices which constituted medical care within the hospital.

In the chapter which follows this one, I go on to consider the divergent responsibilities of families and medical staff towards the care of people who are very sick. I describe the efforts which nurses and patients on the wards go to, not to mimic one another's caring practices, but rather to keep separate the familial and medical care of the very sick body. I suggest that although caring practices in medical interactions within Kagot District Hospital have parallels within the caring practices of the home and family, that this shared repertoire of caring practices exists alongside practices involved in the maintenance of a clear differentiation between these domains of medical care and familial care. Taken together, these contrasting practices, which simultaneously blur the boundary between home and hospital and delineate or re-emphasise it, constitute hospital as a domain of care.

## Introduction

In this chapter I develop a discussion around care and hierarchy which engages with a wider discussion around whether, and if so why, nurses treat patients cruelly in African hospitals. This is a

matter which has been taken up in many recent studies of nursing and healthcare more generally across a variety of African sites, with different authors commenting upon an absence or poor quality of care in hospitals and the abusive or stigmatising treatment of nurses towards patients (e.g. Andersen 2004, Center for Reproductive Rights and FIDA 2007, Gilson et al. 1994, Jewkes et al. 1998, Marks 1997: 28-9, Mwangi et al. 2008, Wood and Jewkes 2006).

Here, I aim to add a layer of complexity to these discussions about abusive or poor treatment. Rather than concentrating on structural deficiencies of the Kenyan health system or an 'attitude problem' of medical staff, as much of this work has done, I question what can be learnt by thinking about interactions between nurses and patients as relationships of care which can be followed into other domains of social life. I do not mean to belittle patients' complaints about the quality of service they received at the hospital, nor to excuse malpractice and cruelty, but rather to underline convergences between caring relationships within and outside of this Kenyan hospital, which elucidate more complex understandings of what constitutes care within this setting.

I use ethnographic material to develop a comparison between the relationships of care found within the labour ward of Kagot District Hospital with one very specific kind of HIV care employed on the general wards, the offering of a diagnostic HIV test to people who showed symptoms suggestive of HIV/AIDS. In the case of the labour room, I argue that the hierarchical nature of relationships of care found in the labour room can be partly understood in reference to the Luo concept of *luoro*. The term *luoro* means both fear and respect and is a domain of social practice which also shapes many other kinds of relationships, particularly at home, for example those between children and their parents. I contrast the hierarchical care of the labour room with the more egalitarian caring practices employed towards patients admitted to the wards who are thought to require diagnostic HIV tests, and suggest that these types of caring relationships also have parallels in kinds of relationships found outside of the hospital. This ethnographic evidence undermines theorisations of care which rely upon an unambiguous conceptual division between emotional and technical care or between medical and familial care.

#### Care in the labour room

In the labour room of Kagot District Hospital, a woman called Pamela lies naked upon a delivery bed. Lying on her back with her knees bent and legs doubled-up, she tightly grips her ankles as she is overcome by the need to push with a contraction. She is frightened, but compliant. Exhausted, she rolls onto her side and drifts into a sleep-like state as the contraction passes. Standing at some distance from her, Sister Carolyn explains to me that they are "testing the scar" – the scar that is, of the caesarean section that ended her previous labour. But the doctor is not nearby, and it is not obvious that there is a potential back–up plan to be followed here, should the 'test' fail. So we wait. The contractions seem to be getting weaker and further apart. Carolyn is reluctant to do an internal examination as she has only one pair of long sterile gloves which she will need later in the delivery. We keep waiting.

I think back to a day earlier in the week, where a visiting nurse from Canada held the hand of a woman in third-stage labour and exclaimed encouragingly, "Bear down Millicent!", at each contraction, showing her concern by touching the woman, holding her hand and encouraging her efforts. The Kenyan nurses in the room had joked, "Today you are lucky, you have an *mzungu* (Swahili. A white person) with you!" I could not help thinking they were right, contrasting the care given by the Canadian nurse with the at times near-cruelty of the Kenyan nurses. Not that Carolyn had slapped the woman for being in the 'wrong position', or 'not trying', as other nurses had done as I watched women in labour. But she certainly did not use touch as a gesture of care and was distant from the woman, largely letting her get on with it, waiting on the other side of the room.

I also thought back to the stories Gaudentia, a Luo friend who I once lived with, had told me about giving birth. It had emerged that our neighbour, feeling the pangs of the final stages of labour, had taken herself off into the vegetable garden where she had given birth alone and cut the cord with a razor she had carried with her, an act that we had both found shocking. It was Gaudentia who first explained to me that Luo women should ideally give birth without screaming; "If you cry out people will say, 'Why are you screaming, you are not the first to feel this pain!", she told me.

Carolyn and I are leaning on the cupboard under the window, looking out over the hospital compound, still waiting to see what Pamela's contractions might produce as she lies alone on the other side of the room. Companions are forbidden in the labour room. My mind passes over these many associations and to my own terrifying experience of delivering my son by emergency Caesarean Section in a hospital in Manchester three years previously, then back to the anxious liminality of a slow and difficult delivery. I turn to Carolyn and off-hand make a joke to pass the time, "In my place we're like everyone has felt those pains so we really feel bad for the woman in labour, but here you're like everyone has felt those pains so why are you crying?!" Carolyn corrects me, "It's true we don't sympathise, although we do inside, because if we sympathise with them they'll relax (i.e. they

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won't push hard enough), we have to let them think it's just normal." And after the longest time, an exhausted Pamela pushes and we see the first sign of new life, a few curls of black hair pushing their way out of her gaping vagina. Carolyn puts on the gloves.

After the baby had been welcomed into the world, wrapped up in a piece of cloth known as *leso*, Pamela, close to tears, thanked us again and again, speaking of her relief and gratitude. Later, as we drank tea together in the nurses' room, Carolyn and I both voiced the doubt that we had kept silent in the delivery room, that neither of us thought it likely that Pamela would be able to successfully deliver her baby. Carolyn also thanked me, "It was a good thing you did there, staying with that woman. You could have left because it was taking long, but it was good that you stayed."

## Harsh and cruel

In Kenya, there is a wide-spread popular discourse that nurses are often harsh and frequently treat patients cruelly<sup>122</sup>. Poor opinions of nursing behaviour can be regularly found in the popular press. For example Dr. Kimani, the director of medical services in Kenya was recently quoted as saying, "The bad attitudes of some health workers are chasing mothers from delivering in hospitals" (The Standard 9th October 2009). In another article a nurse at a mission hospital is chastised for her cruel outburst to a woman who presented at the hospital with a suspected miscarriage:

"If you want to abort your baby then do it on your own time. Don't come here. When you were getting pregnant you didn't call us. You young ladies love sex and when you get caught, you rush here. We do not procure abortions" (The Standard 17th February 2010).

There is no doubt that the Kenyan labour room is often a site of abuse and malpractice. A recent (2007) report developed by the Kenyan Federation of Women Lawyers in collaboration with the American organisation Center for Reproductive Rights compiled a collection of women's birth stories in government facilities which is a veritable litany of mal-practice and abuse. The report describes instances of verbal, physical and sexual abuse of women in labour. Women describe being ignored by nurses and left to deliver alone, being forced to deliver upon dirty beds, being cut with unsterilized equipment and make claims of institutional cover-ups of maternal and neo-natal deaths.

<sup>&</sup>lt;sup>122</sup> Although (perhaps somewhat paradoxically) nursing remains a relatively prestigious and well-regarded profession.

Similarly poor opinions of the labour facilities could be heard in gossip around Kagot. Cynthia Opiyo, an outpatient at Kagot District Hospital, was in no doubt about what she understood as the widespread failings of the hospital. She recounted, "There was a woman who gave birth in Kagot District Hospital who was left with the placenta undelivered and the child on the floor all night. Anywhere else the police would be called!" However, such opinions often contrasted with women's descriptions of their individual experiences of giving birth in the hospital, which tended either to describe encounters of the nurses in broadly appreciative terms, or to focus only on the practical interventions of nurses. When I asked Emily Obonyo if she had been well treated by the nurses who delivered her eighth child during her first hospital delivery, she replied, "Yes, they really helped me, they gave me two bottles of water [intravenous fluids]." Rose Akinyi also outlined the nurses' help in similarly practical terms when I asked how they had supported her in hospital; "My friend knew someone who was a sister at the hospital, and she helped us arrange the bill."<sup>123</sup>

However, let me go back to the ethnographic vignette above, which I maintain is not a description of a relationship of abuse, but one of care. I do not wish to make a judgement about the *quality* of care that Carolyn gives Pamela during her labour – this I think is a discussion for another time and probably for a different kind of observer. Nonetheless, it is probably true to say that Carolyn's management of Pamela's delivery could have been improved, even within the constraints of this resource-poor hospital where women were required to bring with them items such as gloves, cotton wool and cord clamps owing to shortages in the hospital. Nonetheless, I maintain that it is helpful to think about the interaction between Carolyn and Pamela as a relation of care. To do so may be contentious given the potential for and reality of abuse in such kinds of relationships, but one thing that it does allow is to draw attention to divergent registers of meaning around care which are helpful for contextualising the meanings of care and abuse in this setting. If we dismiss Carolyn's behaviour as uncaring I argue that we misunderstand important ways in which care is practised in this hospital.

What is going on between Pamela and Carolyn *is* care. It is other-directed and a process through which Carolyn finds her place in the world through her engagement with and support of another to return to Mayeroff's (1971) definition of care, which I discussed in the introduction to this thesis. Carolyn is providing care which is both emotional (although not close or friendly), and technical (although not necessarily 'good' or 'best practice'). In saving the sterile gloves until the point when

<sup>&</sup>lt;sup>123</sup> These comments are suggestive of the existence of an additional understanding of care which I unfortunately do not have the space to consider in depth here, where an important aspect of the role of nurses is understood to be to distribute the resources of the hospital to patients (cf. Whyte 1992: 6 on nurses as gatekeepers).

they are most needed and drawing on prior knowledge, training and experience of delivering babies, Carolyn judges when and how to intervene and support Pamela's labour process. This is a process of technical care, but it is also an emotional one, as it respects the cost of the gloves to Pamela and her family, who have purchased them prior to her admission to the labour ward and almost certainly cannot afford another pair. It also balances the risk to Pamela (of not doing a vaginal examination) against the risk of HIV infection that Carolyn faces in delivering her baby, a risk that she faces daily in her work in this hospital. Here then, emotional and technical aspects of care are not separate but intertwined – and more fundamentally, in stating the importance of not showing sympathy, Carolyn has announced that it is in fact through the development of a particular kind of emotional relationship that good technical outcomes can be achieved.

I now go on to argue that as a set of practices, the kind of caring relationship I describe between Carolyn and Pamela not only blurs boundaries between technical and emotional care but also between medical and familial care. In the next section I suggest that it is by examining how such practices of care are replicated outside of the hospital that we can make sense of them

#### Hierarchy and care: Luoro relationships in hospital and at home

If Carolyn's declaration, "if we (openly) sympathise with them, they'll relax," is a declaration of care, what kind of care is it? What can we learn about understandings of medical care in this setting when we interrogate this declaration? There is no doubt that across Africa the nursing profession developed within a colonial hegemony which deliberately set nurses apart from those whom they served in an effort to change African subjectivities. For example, Marks argues for South Africa, that the role of nurses was "to moralise and save the sick, not simply nurse them" (1994: 208) and Vaughan (1991) claims that both secular and mission medicine in colonial East and Central Africa were based upon social pathological models of 'sickness' and aimed to influence subjectivities as much as cure illness. Hierarchical relationships between nurses and patients in contemporary Kenya owe much to this colonial inheritance, as well as to understandings of nurse identity and the role of nurses in the British models of nursing which inspired Kenyan training curriculums (Rafferty 1996). These curricula were based upon a class-based hierarchy which was modelled upon domestic service and also upon a gendered division of labour which aligned nursing with motherhood and the care of the sick with the care of the nation (Davin 1978, Rafferty 1996). As Shula Marks has argued so eloquently for South Africa, such hierarchies meshed only too well with patriarchal and racial hierarchies of colonial society (Marks 1997: 30).

As others have noted across a range of African settings, hierarchies between nurses and patients are often overlain with other kinds of hierarchies, most notably class differences between the nurses and those whom they serve (Andersen 2004, Booth 2004: 119-20, Marks 1994: 208). Nursing, along with teaching, is probably the quintessentially middle-class profession in Kenya, symbolising education, wealth and upward mobility. Nurses are well off in comparison to the majority of those they serve in hospitals. These class differences are manifest in everything from the clothes nurses wear and the way they style their hair to the languages that they choose to speak. Because nursing requires post-secondary education, these class differences are embodied in the profession itself. On the wards of Kagot District Hospital even those nurses who ethnically identified as Luo, like the overwhelming majority of the patients, frequently spoke about the patients as though they were cultural outsiders from their life world (cf. Booth: Ibid.).

The existence of hierarchy and authority within relations between nurses and their patients is clearly not confined to Western Kenya. However, the comparison I want to make in this paper *is* a more local one, and one which I suggest is useful because of the way it draws attention to specific associations around care in circulation in this setting. Specifically, I suggest that as a social practice, the kind of relationship seen between Carolyn and Pamela is replicated most strikingly in relationships found between adjacent generations within the home, and other institutional settings such as the school.

As in some other African languages, the terms for 'fear' and 'respect' are combined in *Dholuo*, the Luo language, under a single term, *luoro*, making the two concepts very difficult to disentangle in the framework of the local cosmology (cf. Simpson 2005: 572-3, 2009, van der Geest 1997). *Luoro* is the basis for the relationships between children and their parents, especially fathers, who spend more time out of the home than mothers and who are often physically as well as emotionally distant from their children. Ocholla-Ayayo has described respect for elders as "the driving force" of the traditional education of Luo children (1976: 61).

In the homes in which I spent time in and around Kagot, the everyday lives of Luo children and their parents were often quite separate. Frequently, as soon as a child begins to walk it will be cared for by older siblings (*jopidi* sing. *japidi*) and other female relatives as much as its own mother (cf. Ominde 1987 [1952]). Children usually stay at home while their mothers go out to their gardens, to market, or to earn money, and when they are at home, Luo mothers prefer their children to play outside during daylight hours with other children rather than inside the house.

Although children are encouraged to greet visitors, even when very young, once greetings have finished children are kept away from adult meetings and separated from the world of adult affairs (cf. Blount 1972: 246). When children are asked to greet a visitor, they will approach in a similar way to the way they approach their father, or a respected figure such as a teacher or church leader, with eyes directed demurely towards the ground, only speaking when asked a question and standing rather than sitting in their presence. They thus show their respect by showing their fear. Children do not speak badly of people, such as their teachers, whom they are supposed to respect and avoid speaking to them if they meet outside of school. My informants told me that if a man meets his mother-in-law (a situation ideally avoided) the fear/respect is so strong that he should not even shake hands with her when he greets her.

These patterns of avoidance and distance do not apply in the same way to grandparents, with whom children are in general more relaxed, and with whom they often have much more intimate, joking relationships (Geissler and Prince 2004, Prince and Geissler 2001). Nor do they apply in the same way to siblings and age mates, although age and birth order also stratify relationships in hierarchical ways. In Luo cosmology, the sexuality of adults is thought to present a danger to children. Luo children should not see their parents naked. They should not enter their parents' sleeping area once they have reached the age of seven or eight and they should not be held upon the lap of a grandmother who is still sexually active. It has been argued that these sexual taboos are at the root of the relationship of avoidance between adjacent generations, and equally the closeness and intimacy that exists between alternate generations (Geissler and Prince 2004: 97, Prince and Geissler 2001: 451). It is breeching these relational orders and mixing the sexuality of adjacent generations which is thought to bring the serious and fatal illness of *chira* to the family.

While sexual taboo may lie at the heart of avoidance practiced in the parent-child relationship, it is interesting to note how the practices that exist in these kinds of relationships occur in other hierarchical relationships where there are no such concerns. It seems to me that what is at issue are not simply issues of taboo and avoidance but also more broadly the kind of person which such interactions help to produce. Children in the home are trained in skills which they will need to survive and to become proper people. These include how to relate to others, care for younger siblings and carry out particular tasks around the home. They also include a range of domestic tasks, especially for girls. In the case of boys, they may include responsibility for any animals that need grazing (cf.

Ominde 1987 [1952]). Children and parents expect children to carry out tasks around the home efficiently and without complaint.

Comparably, in the labour wards of the hospital, women need to be taught to give birth, that it is 'just normal', so that they can get on with this difficult task. Carolyn does not cultivate distance from Pamela in order to protect herself from the emotional intensity of such a relationship, as was the case in the advice given to British nurses before nursing models began to reflect upon the benefits of relational 'closeness' in patient care (Savage 1997). On the contrary the cultivation of distance is assumed to create the possibility for a successful relationship of care between the two women.

#### Care, abuse and the proper management of pain

During fieldwork, I found that physical reprimands were often seen as acceptable within *luoro* relationships if such discipline taught people to 'behave properly'. Hearing a child screaming in our compound one afternoon, I came outside to find that Winston, in his early 20's, had slapped John, 8. John was crying with his head in his hands and whimpering.

Hannah:	Why is he crying?
Winston:	You see this boy was checking me [i.e. mocking or back chatting] like he is
my age mate.	
Hannah:	You beat him?
Winston:	Of course! But it was not hard, just a light slap on the face.

Just as children might be beaten at home in order to remind them to enact the child role properly, and some men talked openly about beating their wives if they did not perform domestic tasks adequately, 'disobedient' patients, and especially women in labour, were sometimes slapped by the doctor or nurses.

It is unfortunate that I do not have up-to-date ethnographic observations of women's experiences of giving birth at home in this part of Kenya. However, Ominde (1987 [1952]: 61) noted that birth assistants at home may also slap women if they do not follow their instructions. Certainly, the women whom I knew in Kagot district who had a reputation of being able to assist other women deliver at home (*nyamreche* sing. *nyamrerwa*) were all older women, suggesting that by virtue of age

alone they may have had similarly hierarchical relationships with the women whom they assisted to deliver<sup>124</sup>.

Meanwhile, in the hospital, my informants seemed to be broadly in agreement that physical abuse and restraint, such as tying unruly patients to their beds so they would be still for examinations, were a necessary recourse on some occasions. However, there were certain parameters within which such treatment could occur, and limits to the way this kind of discipline could be carried out. Physical discipline was gendered. Only women were slapped. They were usually women who were in labour or refusing examination. Men might be held down, but they were never slapped. Women were not slapped to deliberately hurt or punish them (which would have been regarded as cruel) but to get them to perform the patient role properly. If women in labour were slapped it was usually on the legs, or perhaps the arms, in an effort to make them hold their legs in the manner which nurses required. It would have been inconceivable to slap a woman on the face, or to hit her so hard that she was bruised, or bleeding. Thinking about some medical encounters as based on *luoro* relationships is helpful, I suggest, in part because it contextualises a range of practices which from outside might be classed as abuse, but in this context are not.

Moreover, there was broad consensus that women in labour should behave in particular ways, in particular by managing pain properly, which meshed with the obligation for the woman in labour to fear/respect the nurses within hierarchical relationships. Emily Obonyo described to me her many labours at home, proudly emphasising her exemplary comportment, "When I give birth I just carry on as normal, I go to my gardens and when the baby is coming I go home. I just call somebody to hold my legs and the baby comes." In rural areas, most women, even when heavily pregnant, continue with work such as gardening and lifting and carrying water. It is only in the period after delivery that women rest and send others to carry out chores for them. A good labour and pregnancy are managed by making them 'just normal', to borrow Carolyn's phrase. Many women I spoke to also reiterated what Gaudencia had told me, that screaming in labour is looked down upon. A number of nurses on the wards recounted the story of how their colleague Sister Christina came and gave birth in hospital, with Sister Hilda confiding, "I would never give birth here! Do you know what happened? Staff on duty were coming to watch her, they were wondering how she will give birth, whether she will scream."

<sup>&</sup>lt;sup>124</sup> This is a matter which would benefit greatly from further investigation in order to examine in more detail similarities and divergences between births at home and at hospital.

# Other kinds of care

In the labour room *luoro* was the standard kind of interaction. Nurses did not touch women in first stage labour, who were told simply to walk around to ease the pain. In third stage nurses touched women only to move their bodies into the right position. Words such as stubborn, difficult and uncooperative were frequently heard about labouring women:

A woman has been admitted with prolonged labour. The doctor performs a vaginal examination in the labour room. He tells her to lie properly and hold her legs in. She's lying naked on the left hand bed. The assisting nurse, Onyango, goes over and holds her head, 'lie straight!' he says, and grabs her leg. 'Move the other one too!' he orders. Field notes September 4<sup>th</sup> 2006

Peter, who is the mortuary assistant, walks into the labour room and says "tut-tut" when he sees the woman in labour. Carolyn complains that she's very stubborn and not cooperating. The woman pushes many times and each time Carolyn tells her to hold onto her legs and each time the woman refuses and holds on all over the place, rolling around the bed screaming. When she refuses to hold her legs Carolyn slaps her arms and legs. Field notes  $22^{nd}$  August 2006.

Yet even in the labour room there were occasional moments where there were other kinds of care. Sister Rachel kindly delivered tea into the labour room prepared by family members for a woman in long labour. On another occasion when Carolyn was delivering a woman who was not "cooperative" another nurse came into room and took hold of her hand, telling her gently, "The baby is getting tired you need to push hard."

However, caring practices in the labour room stood in marked contrast to other kinds of medical care provided in the hospital. To give one particular example, they contrasted with the way in which nurses and doctors dealt with the need to request patients' permission to test for HIV.

Many of those patients who were admitted to the hospital were HIV positive, and some were dying of AIDS. Patients who were suffering from illnesses common in HIV and who did not know their HIV status were usually referred for HIV testing on the wards. However, despite the ubiquitous nature of HIV/AIDS on the wards, everyone who worked there took immense care to avoid talking directly of HIV and AIDS and of the need for HIV tests. HIV tests were referred to as 'DTCs', which stood for Diagnostic Testing and Counselling, or 'serology'. HIV+ patients were described as being 'reactive'.

"Is this condition common in ISS (Immuno-Suppression Syndrome)?", I learnt to say when following the doctors on their rounds. Or, "Has he tested reactive?"

Sister Amanda comes in and takes William, one of the patients, for his DTC test. When she asks him to come she just asks him, "Can you walk? I want to go with you outside to discuss something." Field notes 9<sup>th</sup> September 2006

The doctor asks the patient if he attends the PSC [the Patient Support Centre, where HIV care is provided]. The patient shakes his head and after listening to his chest the doctor says in Swahili, "Sister will come here and talk to you and test your blood." Field notes 4<sup>th</sup> Sept 2006

The Doctor comes to the last man in the ward who is sitting up in bed. He asks him, "Are you sick?" He replies in the affirmative. He tells doctor that he came yesterday because he was coughing a lot and he had a terrible pain in his chest. The doctor looks at his x-ray and then says to him in Swahili, "You have TB." He continues, "You will go down there to the chest clinic [points to the other side of the hospital compound]. They can also test [pause] your blood. It's not a must, only if you want." Field notes 25<sup>th</sup> August 2006

When I asked the doctor why they used this guarded euphemistic language about HIV in the hospital he replied to me, "People don't like it [if you talk about their HIV status]. They will say, 'You were discussing me with a foreigner.'" While this coded language certainly owes something to issues of stigma around HIV/AIDS, this cannot wholly explain the marked difference in types of care within the hospital context. After all nurses could have cruelly revealed people's HIV status, had they wished. Susan Reynolds Whyte (1997: 217-9) has characterised similar kinds of talk in Eastern Uganda as "care-ful" talk, underlining how family members and loved ones underline sympathy for their sick by avoiding the harshness of a definitive diagnosis.

I suggest that the difference in caring practices noted here lies in the fact that unlike in the labour room, where outcomes are uncertain and nurses claim that a particular kind of emotional relationship can facilitate the labour process, in the case of HIV testing, the outcome (a HIV+ test result) is generally known prior to the giving of the test. Medical staff in Kagot District Hospital had become experts in recognising the signs of suppressed immunity. Those patients who were referred for HIV testing rarely tested negative. The interaction between medical staff and patients in the case of diagnostic HIV testing did not have the urgency of creating a particular kind of person which would enable a potentially difficult care outcome to be achieved. For this reason medical staff could respect people's feelings and desire for privacy and behave in a more 'relaxed' way with these patients.

My point here is that, in an interesting parallel with care in the domestic domain, medical care seemed to consist of both *luoro* interactions and more egalitarian ones. While it was true that egalitarian relationships were less often found between doctors or clinicians<sup>125</sup> and patients than with lower level hospital staff, it is also true to say that certain *kinds* of medical interaction were much more likely to be *luoro* than others. Medical care did not consist of a single type of care, but changed according both to existing hierarchies between patients and medical staff as well as the kind of care deemed appropriate for a particular situation. This analysis also sheds light upon the hierarchical relationships of care which I documented in the Patient Support Centre in the previous Chapter, where staff were also concerned with encouraging the development of particular kinds of people.

## Conclusion

In earlier chapters of this thesis I discussed the development of home as a domain of care, focusing upon Home-Based Care as a governmental intervention which has emerged as one major response to the HIV/AIDS epidemic. I argued that Home-Based Care allows those who do it to build up both individual distinction and relational capital. I went on to argue that Home-Based Care is also made credible as a set of policy interventions because of the way it resembles and links to previous policies and experiences of government and the governability of home.

In the governmental conception of Home-Based Care, a key point is that Home-Based Care draws upon and creates a certain imaginary of home as a domain of care by juxtaposing it to a contrasting domain of care, that of hospital. These distinct domains of care are not equal in the policy imaginary, as Home-Based Care is understood as "an extension of clinical care", and Home-Based Care programmes are often managed by health professionals even though they are usually carried out by people without formal medical expertise. However, the central concept of Home Based Care is that home can (and perhaps should) provide the context for a certain kind of care which hospital cannot provide. This model of care draws upon notions of community solidarity and the appropriateness of familial labour in the care and support of the terminally ill.

<sup>&</sup>lt;sup>125</sup> In Kenya, Doctors are distinguished from Clinicians. Both are allowed to prescribe medication but Doctors are more senior than Clinicians and have received more training at medical school.

My argument in this chapter has been that hospital also develops as a domain of care in relation to home through similarities between the kinds of practices which constitute relationships of care in each. Practices of care at hospital and home point to two dominant models of care in Luo society which might be glossed as *luoro* and egalitarian care. In the context of Kagot District Hospital, *'luoro* care' and 'egalitarian care' did not map upon a simple division between medical care and familial/emotional care. Nor could they be easily labelled as either emotional or technical, but on the contrary cut across these domains. I demonstrated that *Luoro* care, for example, was based upon a particular kind of relationship of emotional distance. Good care outcomes were thought to be made possible through the correct application of these two types of care, each of which seemed to properly belong within particular spaces and relationships and to the proper enactment of particular roles, making the provision of 'good care' relationally and contextually contingent. In this understanding of care created through relationship and practice, closeness and intimacy were not always the right kind of care needed to produce particular outcomes. In some situations they were understood as detrimental to the provision of good care.

# Chapter 7. Hospital Domestics: Care work on the wards

### Introduction

In this chapter the focus shifts to practices of care within the hospital wards, where I compare the differential types of care provided for sick people by medical staff and families. In Kagot District Hospital, as is the case in many other African settings, it is common for caregivers to live alongside patients who are admitted to hospital. The ethnographic evidence I present in this chapter describes how in the context of hospital admission, proper care for patients required both the mobilisation of the extended family and the care and attention of hospital staff.

Considering the relationships between practices of care and marked institutional and architectural spaces, I draw on the concept of 'spatial practice' to argue that caring practices created ward spaces which were both medical and domestic, with patients the objects of two divergent models of care, which I call 'familial' and 'medical', aligned to these spaces. Although, as I argued in the last chapter, medical staff drew upon repertoires of practice in the way they cared for patients which had correlates with the caring practices of home, in this context caregivers and hospital staff emphasised the boundary and difference *between* these models of care to comment on and (re)produce concepts of responsibility and obligation to others and also to legitimate restrictions that they placed upon the care they gave. I suggest that these are not contradictory practices, but rather different aspects of a complex topography of care.

The evidence presented in this chapter suggests that it is helpful to think about the domestic as a mobile sphere of practices and relationships related to, but not necessarily fixed to the home, just as 'the clinic', as a set of practices, relationships and associations extends outside the hospital. I argue that it is helpful to think about the wards of this hospital not as a biomedical space punctuated by practices from outside, but rather as a contested institutional space produced through a composite of spatial practices which include both medical and domestic practice.

### Into the wards

During my fieldwork in Western Kenya, the time I spent on the wards of Kagot District Hospital was the most difficult. It was as though one entered another world when one stepped into the stinky, run-down wards of this small Kenyan hospital. The architecture of the hospital wards, with its small rooms off long corridors, physically set it apart from other kinds of buildings in the town. The colour scheme of the paintwork and veranda-fronted bungalow design of the building resembled other health facilities across East Africa and were a visual alignment with institutionalised biomedicine. The darkness inside was a shock after the bright sun outside, momentarily blinding and unsettling.

Outside of visiting hours a small wooden gate into the wards was kept locked and one had to negotiate with staff to be allowed entry. Most of those who worked in the wards wore uniforms, in colours and styles which signified their status in the hospital. Nurses and Doctors used a coded language to discuss patients, mixing medical terminology and abbreviations with euphemism.

Moreover, patients' conditions were shocking; an untreated abscess that had eaten away half of a woman's face, broken bones that had never been set, a leg wound on a child that had become so badly infected the bone was visible and would probably need amputation, a hand cut off in a fight over land. In stark contrast from the 'world outside', death, disease and despair were transformed from the extraordinary into the everyday. Matters of life and death were both magnified and normalised. After the death of a baby the doctor on duty calmly continued a conversation we had been having before the worried mother had rushed into the room carrying her sick daughter wrapped in a blanket, as though the world were no different for its loss. And whilst the joy at the successful management of a complex delivery or an unexpected recovery was genuine and shared by family members and hospital staff alike, within the wards such moments of joy were quickly superseded by other concerns and events.

Sometimes it seemed to me that all of these barriers and differences could be summed up not so much in the foreign-yet-familiar work of the staff on the wards, nor the bodies of people who drifted in and out of the uncertain space between health and illness and between life and death, but rather in the terrible smell that hit like a hard punch in the stomach as one entered the wards; a stench of death, decay and bodily excretions mixed with the pungent odour of the soap used to clean the floors every morning. A smell so bad I had been warned about it by the staff in the support centre;

Belinda comes back from her break and asks, "Eh! What is that smell?"

Jane:	A woman was here from the ward.
Hannah:	But why did she smell so bad, <i>alihara?</i> [did she have diarrhoea?]
Jane:	No, you see if you spend two hours there, you stink.
Hannah:	Sothose wards are not clean?
Jane:	No I don't think that they are cleaning the wards with nini [Swa. what?].
Belinda:	Antiseptic?
Jane:	Ee [Yes]. They are just using water and Omo [a brand of soap powder].
Belinda:	That's bad, they should be using antiseptic. (Field notes 19/04/2006)

There could be no doubt that the wards constituted a medical space, underlined by particular kinds of practice and authority. And yet, within the same building which cultivated the stench that recalled the ailing body, there were other kinds of objects and activities that recalled another kind of place. All around were signs of home, family and faith. Family members frequently outnumbered patients on the wards. Caregivers slept on the hard, dirty, stone floor of the hospital to provide their loved ones with constant care. Hospital beds were surrounded by the trappings of home: food, basins, blankets, clothes, bibles.

In the wards of this hospital, proper care for patients required the attention of both family members and hospital staff. It is the interplay between these two divergent models of care, which I call medical and familial, and the making through practice of the boundary between these types of care, which is the subject of this Chapter. My contention is that the boundary between the hospital wards and the outside world is an important analytic and representational device for making sense of this underresourced hospital as an institution. However, in this hospital the medical realm did not map easily upon this boundary but was instead produced by particular sets of practices *within* the hospital. I argue that the ethnography presented here undermines an easy association between biomedicine and the hospital as a composite of the divergent spatial practices of the medical and familial that one can make sense of this hospital as an institution; as a space where practices are organised via particular, sometimes conflicting, kinds of authority.

### **On hospital spaces**

Since the publication of the sociological studies which marked the beginnings of the genre 'hospital ethnography', the issue of what kind of space constitutes a hospital has been a point of interest and

debate. Ethnographic work on hospitals of the 1950s and 1960s consisted mostly of considerations of hospitals in 'Western' settings and dealt primarily with a 'hospital culture' presumed to take place in a bounded social space very different from the 'world outside' (van der Geest and Finkler 2004: 1998). In this literature we find the hospital described as "a tight little island" (Coser 1962: 3), and in the case of the psychiatric hospital as a "small society" (Caudill 1958) and most famously, a "total institution" (Goffman 1961), "symbolized by the barrier to social intercourse with the outside world" (Ibid.: 15).

A special edition of *Social Science and Medicine* on hospital ethnography was the first major collection of international hospital ethnography to question the related assumptions of biomedicine as a homogeneous global culture and of hospitals as the more or less identical products of this culture (van der Geest and Finkler 2004). The authors of this collection drew particular attention to the porous nature of boundaries of hospitals and emphasised that hospitals around the world are places that reflect and reinforce dominant local social and cultural processes, for example those of social hierarchy (Andersen 2004), and those of gender relations and endemic poverty (Zaman 2004).

Many of the same authors have returned to these issues in recent special editions of *Anthropology of Medicine* and the *Journal of Contemporary Ethnography*, developing the discussion with a more nuanced set of arguments reflecting upon the ambiguity of hospital space. They considered the ways in which hospital space is simultaneously set apart from the world outside *and* culturally embedded, for example by using Turner's (1967) concept of liminality to think about the process of hospital admission (Long et al. 2008 72-3), or by considering the ways in which multiple meanings are inscribed upon hospital spaces (Horsley 2008). Elsewhere, others have employed Foucault's (1977 [1975]) analysis of Bentham's Panopticon as the architectural mechanism for surveillance and control *par excellence* to comment upon the ways in which surveillance is used to discipline minds and bodies in hospital settings (Gibson 2004, Moland 2002: 137-9, Rhodes 1991: 22).

In this chapter I develop my earlier claim that caring practices are often spatial practices. I draw upon a post-structuralist understanding of space which views space and social practice as interrelated and co-constitutive, rather than viewing practice as something played out upon, or within, particular spaces, as though space is somehow prior to social action (Ingold 1995, Massey 2005). This standpoint does more than suggest the need to think about space in terms of the relations that make that space, but importantly goes on to suggest that the social cannot be understood without thinking about relations in a fully spatial way (Massey 2005: 39). Although space and spatial practices have been an ongoing concern within ethnographic work on hospitals, the point at which the studies cited above share common ground is in a tendency to confine this spatial thinking to consideration of the boundary between the hospital and the 'outside world'. The difficulties with such a position are highlighted by the recent trend in understanding the boundaries around hospitals as porous (e.g. Zaman 2004). Although porosity enables a helpful corrective to understandings of hospitals as the homogeneous products of a global medical culture and to the bounded totality of the 'total' institution, it is a frame which nonetheless imagines certain practices from outside moving inside, as though crossing a fixed, if permeable, boundary. The porous boundary thus replicates more-or-less the same conceptual division as the fixed boundary, precisely because it imagines a boundary across which practices can move. In particular, the porous boundary retains the problematic supposition of earlier work that there is an easy correlate between 'the medical' with its corresponding power and authority and 'the hospital', alongside the corresponding assumption that it is the 'medicalness' of the hospital which makes it different from other kinds of spaces.

I suggest that most hospital-based ethnography has taken this boundary for granted, focusing upon it to the detriment of other kinds of spatial theorisation of hospital spaces. In this chapter I use the prism of care as a framing device show how spatial practices of care produced a boundary around medical authority *within* the hospital. Such practices were not unrelated to the production of the boundary between the hospital and the outside world and on the contrary were imbricated with the production of the perimeter boundary. However, spatial practices in this hospital were in no way limited to the production of this external boundary.

Practices of care are particularly suited to this kind of spatially aware ethnography for a number of reasons. Firstly, the hospital building represents the architectural evidence of the production of particular kinds of authority over the organisation and provision of care (Langwick 2006: 150-4, Prior 1988), as do many of the hospital's bureaucratic practices. Secondly, care is the unqualified object of many of the practices that take place inside the hospital. More fundamentally however, care is a useful analytic prism because, as I have argued throughout this thesis, as a set of practices care is not defined exclusively by biomedical practice but cuts across many domains of human life and particularly, as I have noted throughout this thesis, into the realm of the domestic. Following practices of care in this hospital shows that this hospital is a place made meaningful (and made to work) through a composite of spatial practices, of which medical practice is just one. This position

allows me to move beyond a crude conjuncture between the hospital and bio-medicine and to consider multiple kinds of hospital space/practice and how they relate to one another.

There are of course many different kinds of activity that go on within any hospital that could be classed as care, ranging from highly specialised interventions such as surgery to a gentle, loving touch. In this chapter I take care in its broadest sense to be the interested, engaged concern for others. However, I do not attempt here to discuss *all* types of caring practice that took place within the hospital wards. Rather, because the data which I collected during fieldwork suggested that boundaries around obligations to care were enacted in particular through the divergent practices which took place around the care of the very sick or dying, it is this kind of care that provides my focus.

#### Spatial practice on the wards: making medical spaces

Patients who were admitted to the wards received medical care in the hospital in various ways. They were seen by one of two male doctors most mornings and, depending on their condition, also received varying levels of attention from the predominantly female nurses. Four or five nurses were on duty during the day and two at night. The caring duties of nurses were divided as follows: In the mornings, one nurse was allocated to assist the doctor on his rounds. The doctor wrote in the patients' notes any changes to their condition or medication while the nurse wrote treatment interventions in a separate book, and also assisted the doctor with any medical procedures. If necessary, another nurse would assist labouring women, and a third would have the task of cleaning and dressing wounds. A nurse 'on treatment' was responsible for dispensing medicines from a trolley that could be pushed around the wards twice daily, with nurses on night duty repeating the activity in the evening and each referring to the notes in the treatment book. If there were any remaining nurses on duty they would be allocated to 'general nursing' and would carry out tasks such as removing drips, managing admissions and collecting items from the store and the pharmacy. This division of labour often ran smoothly. At other times the working day on the wards was punctuated by debilitating absences (both authorised and unauthorised), shortages of staff and equipment, and claim and counter-claim of inefficiency and ineptitude.

The care work done by nurses and doctors revolved around their mastery of hospital processes (most prominently visible through activities involving writing) and their proficiency in the use of certain medical technologies, whose repertoire included the syringe, the bandage, gloves, the stethoscope and certain test procedures. The nurses and doctors' activities within the wards underlined their differential authority, to the extent that 'the medical' became more or less synonymous with this layered authority (cf. Ferzacca 2000, Freidson 1970, Pappas 1990). In defining and controlling the medical sphere, hospital staff could force patients to adhere to processes of hospital administration and to behave in particular ways, for example during examinations where patients were required to be still and compliant, regardless of any pain that they felt.

One particular object around which medical authority coalesced was patient files. Files ordered the flow of patients into and out of the wards as well as providing a place where medical treatment was summarised. Files represented a considerable expense for patients<sup>126</sup> but nurses met patients' inability or disinclination to purchase a hospital file without sympathy. The command, *"Go and buy a file"* spoken in Luo even by non-native speakers<sup>127</sup>, was perhaps the most frequent sentence spoken to patients, at times combined with a threat to withhold care; *"The doctor can't do the work until you have a file."* Files on the wards were confidential, underlining both the esoteric nature of the medical and the power of hospital staff, who were allowed to read and write in them, *vis-à-vis* patients, who were not. They also represented hierarchies of labour within the hospital. Following admission, doctors but not nurses wrote in them. The file was the tangible evidence of the process of hospital admission and in some ways stood in for patients– files were supposed to be purchased on arrival, they provided a space to document the patient's stay in the hospital and when the patient left, discharges or death certificates were withheld without them. The contents of files were used to calculate the final bill due for admission and as an informal documentation of death when nurses closed them by drawing a Christian cross on the front of the file and writing the letters R.I.P. across it.

These practices and objects produced a medical realm which was incontestably the territory of doctors and nurses, to which patient access was highly limited. Nurses and doctors rarely discussed a patient's condition with them and patients did not question doctors and nurses. Nurses and doctors also gained power because they were periodically absent or distant from patients, behaving as 'gatekeepers' of valued services (cf. Whyte 1992: 6). At certain times of the day a patient waiting for a drip to be changed or a line to be removed had to work hard to enlist a nurse to do this. If the doctor was not on hand to sign a discharge form or death certificate, a patient without personal

<sup>&</sup>lt;sup>126</sup> Files cost 80 Kenya Shillings. At the time of field work there were between 120-130Ksh to 1 GBP Stirling. This was a considerable amount for people admitted to hospital, some of whom had very limited access to monetary income of any kind.

<sup>&</sup>lt;sup>127</sup> Fieldwork was carried out in English, Swahili and Luo.

contacts in the hospital might end up staying another night or two in hospital until he was available. In addition to this, doctors and to a lesser degree nurses, could move through spaces in the hospital to which patient access was restricted. These spaces also reflected internal hierarchies. The Medical Superintendent, who ran the whole hospital, had a huge office, his deputy the Medical Officer a slightly smaller one. The nurses shared a small room with a table where they sat to take tea during breaks. What was crucial about these spaces was not just that patients could not freely access them, but that they had to wait obediently on the peripheries of those spaces in order to get things done.

The boundary of medical authority was interwoven with class differences between the nurses and other medical staff and those whom they treated (cf. Booth 2004: 119-20, Marks 1994: 208). Nursing, along with teaching, are quintessentially middle class professions in Kenya, symbolising education, wealth and upward mobility. As I suggested in the last Chapter, nurses are well off in comparison to the majority of those they serve in hospitals. In Kagot, the nurses' bright white uniforms, hair styled in fashionable braids, wigs, expensive perms or salon blow-dries and their smart black leather shoes contrasted with that of female patients and caregivers who covered their hair and in lieu of expensive shoes wore flip-flops or 'rubbers'. While the nurses and doctors primarily switched between the two languages of education in Kenya, English and Swahili, patients spoke mostly Luo and less often Swahili.

Alongside the control of objects and spaces in the hospital, the boundary around medical practice/authority was further reinforced violently through the disciplining of 'bad' patients, who included those who could not control their pain and those who were not acquiescent when the doctors and nurses wanted to work on their bodies. As I previously mentioned, women in childbirth were smacked around the legs if they were in the 'wrong position' to give birth and unruly patients who would not lie still for examination might be tied to the bed, slapped by the doctor or subjected to verbal abuse.

However, despite the powerful and occasionally violent authority of the medical, the medical realm was in no sense 'total' (Goffman 1961) but rather existed alongside other kinds of authority within the wards. Here, the authority of the family and the domestic realm could at times undermine, but more often existed comfortably alongside, the medical, and indeed emphasised the boundaries around it, in particular those concerning obligations to provide care. The work of the nurses on the wards did not involve washing patients, helping patients to use the toilet, feeding patients who could not eat by themselves or turning bed-ridden patients. This care was provided by family members.

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Nurses I spoke to about their duties suggested that these kinds of hands on tasks *were* part of what they considered to be nursing care, but that they did not have the time to do them. For example, as we sat together in the nurses' room preparing bandages for sterilisation, Phyllis explained to me;

"In fact those are our duties, but we are forced to leave them. We are so busy here and even this work we are doing now, it is supposed to be done by subordinate staff but they are not here, so what can we do, we can't tell carers to fold bandages, so we leave that work to them."

Yet even when the wards were not busy, I never saw nurses get involved in this kind of care work. In practice all of these tasks were considered to be the responsibility of family caregivers. Moreover, there was a shared sense between nurses and patients that it was more appropriate for family members to manage this hands-on care of the body. Practices of care in the hospital underlined a distinct boundary between a familial body and a medical body that required different kinds of intervention from different types of people. A nurse might respond to a request to urinate with, "Let me go and find someone to help you," or ask a woman receiving only intermittent care from her husband, "Don't you have somebody at home you can call to help you?" These are caring comments in that they engage with patients' needs, but they delineate care in ways which distinguish between a type of care which is domestic/close/involved with the body from another which is medical/distant/aloof and protected from the body.

The division between the familial and medical body was also critically interwoven with nurses' concerns about the risk of contracting HIV from patients on the wards. The nurses dealt with this daily risk by limiting *all* types of closeness to patients' bodies and in particular any unnecessary physical contact. Nurses wore gloves almost continuously, and certainly when touching skin, even when it was not broken, or other parts of patients' bodies or clothing (cf. Moland 2002: 160-2). Nurses perhaps did reduce their risk of contracting HIV by limiting physical contact with patients and leaving to family carers the dirty bodily caring and management of diarrhoea, vomit and urine, but I would suggest that it was not the risk of HIV *per se* which created this boundary between the two types of care; rather that HIV risk intensified the importance for nurses of maintaining the boundary between familial and medical care.

No-one was entirely exempt from the authority of the familial. The competent but youthful and somewhat diminutive Dr. Okumu at times struggled to maintain his professional authority. Older, experienced nurses complained about his "seriousness" behind his back and some swore they would 189

put in for a transfer if he were ever promoted. Patients also found it difficult to deal with the combination of authority and youth he embodied. One morning an old woman who lay patiently while he carefully cleaned a nasty wound on her lower leg gently mocked him, *"Erokamano nyakwara"* (Thank you my grandson), she said as he finished his work, her generational tease a sign both of affection and gratitude for his care whilst undermining his influential position and reminding him of the existence, even within the hospital wards, of the alternate kinds of authority of age and relation to which I now turn.

### **Being admitted**

Angelica and her sister Akoth spent over a month living in Kagot District Hospital. Both women were young, in their early 20s, but dealt bravely with the unspoken likelihood of Angelica's approaching death. When I came to know her better Angelica confided to me her deepest dream, to be well again.

Angelica and Akoth lived some distance from the hospital in the neighbouring district, but had travelled to Kagot District Hospital because their maternal uncle had a senior administrative position at the hospital which they hoped would entitle them to preferential treatment. This it almost certainly did, but it could not change the fact that Angelica's young body was wracked with tuberculosis and was increasingly too weak to cope with the strong medicines used to treat it. She vomited almost every time that she tried to eat. She was crippled by AIDS. In Kagot at the time ARV treatment was advised for patients whose CD4 count went below 250 mm<sup>3</sup>. The scrap of paper on which Angelica's test results had been written announced a CD4 count of 8 mm<sup>3</sup>.

Akoth cared for Angelica constantly, leaving her side only briefly to fetch clean clothes or food from her uncle's home and for a few stolen moments in the evenings when she relaxed outside with other caregivers. Mostly the sisters talked and kept one another company, but Akoth also lovingly washed Angelica in a pair of basins next to her bed, helped her to dress and eat and ran errands for things that she needed. Akoth did everything she could to make Angelica comfortable, happy and well, but sadly, Angelica died in hospital some months later following a readmission.

Despite the high disease burden in Kagot District, the hospital is one of the least well-equipped district hospitals in the country. At the time of fieldwork, the hospital had twenty beds in its 'General Wards' (four small rooms off a narrow corridor) eleven in the two Acute Wards (which were divided

into separate male and female rooms)<sup>128</sup>, eight Maternity and six Paediatric Beds. In a hospital with a total of 45 beds, the numbers of patients admitted at any given time ranged from the mid 50s to the mid 70s, forcing patients to share beds by sleeping top to tail, especially in the Female Acute and Paediatric Wards, which were particularly overcrowded. In the case of the latter it was not uncommon to find three children in one bed. Medicines, gloves and simple materials such as cotton wool were usually (but not reliably) available and much basic equipment was lacking or broken; the wheelchair had only three wheels. "Even our wheelchair is lame!" the nurses joked. There were only two working taps in the whole building, neither available for the use of patients and their caregivers who fetched water from tanks outside.

People using the hospital wards included those who lived in the surrounding township who were involved in small businesses, petty trading and some professionals such as teachers or civil servants and more successful business people. Those who travelled from further afield, representing the majority of patients, were mostly small-scale farmers and less often fishermen who worked on nearby Lake Victoria. A private nursing home and a number of private clinics in the town provided a choice of health services for some people with a monetary income, but the district hospital was the cheapest and only option for many people, including some who might be termed middle class. Not that the hospital was particularly affordable. A complex system of charging was in place which combined length of stay, medication used and interventions undertaken. Generally speaking, people struggled to raise funds to pay their hospital bill upon discharge.

### Caregivers and patients: Making domestic spaces

Very little has been written about those people like Akoth who live in hospital to help care for patients, although I understand through anecdotal evidence that the practice is common across Africa, as indeed it is elsewhere (Zaman 2004). Studies of care-giving to people living with HIV/AIDS have focused on provision in the community or home setting (Alubo et al. 2002, Awusabo-Asare 1995, Chimwaza and Watkins 2004, Mathambo Mtika 2001, Nnko et al. 2000) rather than the hospital, although arranging visits to the hospital is recognised as an important part of such care (Chimwaza and Watkins 2004: 802, 804, Mathambo Mtika 2001: 184, Ndaba-Mbata 2000: 219). Most references to this practice exist as asides to other work, with the presence of caregivers generally

 $<sup>^{128}</sup>$  The general wards (also referred to as chronic wards) were wards for people with infectious illnesses, mostly HIV/AIDS. The acute wards were for people suffering from non-infectious illnesses and accidents. There were no isolation facilities for those with TB, who were housed in the general wards, sometimes next to other HIV+ people who were not suffering from TB.

seen as a result of the poor quality of services offered by the hospital (Holden 1991: 80-1, Mathambo Mtika 2001: 184).

When I asked caregivers why they lived in the hospital with their patients they often used an economic model of explanation, emphasising that having a full time caregiver present was the only way to get proper care because of the lack of facilities and inadequate nursing care at Kagot. However, they also drew on a cultural model suggesting that 'Africans' had to help their families, for example stating simply, "She is my sister," in response to my question.

Almost all patients admitted to hospital at Kagot had someone caring for them there full-time and patients without caregivers were described as being "abandoned by their relatives". Caregivers were almost always kin, and were predominately female. Wives or mothers were seen as the ideal carers for men. Mothers, sisters, and less often, daughters<sup>129</sup>, were the ideal carers for women. Children and young people were not expected to be able to do the very difficult work of care giving. Judith was the only person who described being cared for by a friend and she drew upon a relational model to describe this care, "Oh!" she exclaimed, "She gave me all the love. You would think she was my sister!"

Caregivers washed, dressed and fed their patients and helped them to the toilet if they could walk to the pit latrines outside, or lifted a *leso*, a piece of multi-purpose cloth (probably *the* quintessentially feminine object across East Africa, also known as *kanga* or *kitenge*), so their patient could squat behind it over a plastic basin. Although some drugs were kept in the ward, caregivers were frequently sent to buy medicines and medical equipment such as intravenous giving sets from the hospital pharmacy where they were sold drugs at discounted prices or from the better-stocked local pharmacies in the town centre. If the doctor ordered an x-ray, usually to check for TB, it was the caregiver's responsibility to find the wheelchair, lift the patient out of bed and wheel them to the x-ray room. It was also the responsibility of the caregiver to find money to pay for these items. Sometimes patients would wait for hours for people to come from home to bring them money or lie in bed without receiving medication while relatives at home organised collections to pay for medical supplies. As van der Geest noted of his own experience of being admitted to a Ghanaian hospital, "A relative attending the patient was...indispensable (van der Geest and Sarkodie 1998: 1375)".

<sup>&</sup>lt;sup>129</sup> Some people told me that daughters should not provide intimate care for their mothers, that it was *chira* for daughters to see their mother naked. Others disagreed.

In studies from across the African continent it has been widely recognised that women, particularly older women, are more likely to be the main carers for people in the later stages of AIDS and indeed for the sick in general (Chimwaza and Watkins 2004, Nnko et al. 2000: 797). In the Luo context high value is placed upon women's labour, which includes care work (Hay 1976: 93, Hoehler-Fatton 1996: 111) and which is implicated in the management of a family's health to the extent that Prince and Geissler have described the treatment of illness as primarily a female domain among Luo people, "People say that women know more about illness that men "because they give birth" (i.e. they have to care for children)" (2001: 453-4). In Kagot District Hospital, a male caregiver was usually in the hospital because his wife was at home with young children or was not physically capable of doing the care giving work in the hospital. Men caring for other male relatives or children behaved much like female caregivers. They stayed full time in hospital and helped the patient with food, buying medicine and so on. However, on the rare occasions where men were caring for their wives, cultural prohibitions restricted them from providing any intimate care and from sleeping in the hospital. Instead they visited intermittently. While male caring was not unacceptable it certainly was not seen as ideal. I asked Evans, a man in his forties, why he was the one looking after his 10 year old son in hospital;

Evans:I'm his father...his mother is minding the house. I'm an old man. I don't<br/>know how to make food [ $ugali^{130}$ ] for children.[Another patient, Ambrose, interjected]Do you have only one wife?Evans:Yes.Ambrose:That's bad.Evans:[laughs] Very bad!<sup>131</sup>

It is probably true to say that there is not a Kenyan alive over the age of five or six who does not know how to cook *ugali*, the country's staple food, so Evans' comments should be read as pointing to the notion that it is easier for him to stand in for a woman in the hospital than it would be for him to stand in for a woman at home. Both are possible but neither desirable. Patterns of care-giving in the hospital thus underlined ideal marital relations. They also underlined the value accorded to having children. While there is considerable variation of family size and uptake of family planning among Luo people, (Rutenberg and Cotts-Watkins 1997) particularly according to class, many Luo people

<sup>&</sup>lt;sup>130</sup> A stiff porridge made from maize or millet.

<sup>&</sup>lt;sup>131</sup> Translated from Swahili.

place high value upon families with many children (Kaler and Cotts-Watkins 2001, Pala Okeyo 1980: 191, Shipton 1989: 19). I asked another woman, Margaret, who was caring for her elderly sister, whether her sister had any children,

Margaret:No. She never gave birth. If she had children, her children would be herenow. You see how it's good to give birth?Hannah:Yes, I see132.

These anecdotes emphasise how the domestic ideal of the polygynous family with many children is (re)valued through the experiences of providing care in times of crisis. As I mentioned earlier, David Parkin used his ethnographic account of the urban migration of Luo people to Nairobi in the 1970s to argue that although the institution of polygyny among Luo people may have been modified through experiences of modernity, it nonetheless remained a viable institution for Luo people, which not only retained the metaphorical significance of wealth and respect associated with 'tradition' but also allowed people to manage the economics of the modern world (Parkin 1978). We can make a similar argument here. The polygynous family may be blamed as a 'cultural problem' complicit in the spread of HIV/AIDS among Luo people, both because polygyny is assumed to open people up to large networks of sexual relationships and because of the relationship between polygyny and the practice of widow inheritance as discussed in Chapter 2. However, we can see here how the contemporary experience of AIDS has strengthened the institution of polygyny and the idealised familial structure of the supportive polygynous family with many children<sup>133</sup>, providing access both to women who could do care work and to networks of pecuniary support<sup>134</sup>.

<sup>&</sup>lt;sup>132</sup> Translated from Swahili.

<sup>&</sup>lt;sup>133</sup> As such, it was seen as a familial arrangement which equally benefited women and men. However, women particularly placed high value upon matrilineal kin, given the enduring tendency, especially in the rural areas of Kagot district, towards virilocal post-nuptial residence and the corresponding structural weakness felt by women, particularly younger women who had not had time to build deep and lasting relationships with their husband's kin and/or failed to produce many children. In this context, matrilineal relatives, particularly sisters, were especially valued by women. In Kagot District Hospital women's maternal kin would sometimes travel from great distances to assist them in hospital.

<sup>&</sup>lt;sup>134</sup>These networks were enlisted to take patients to hospital; arrange a caregiver; help pay hospital bill; buy medicine and help support other family members while the caregiver and patient were unable to work and obtain food/money for the family

### Mobile domesticity

Within the hospital wards, then, relatedness to others was suggested by the presence of carers, visitors and the networks of support that these people engendered. It was also emphasised through the presence and use of particular objects, just as the medical realm was. Because there was very little privacy in the hospital wards (for example curtains around beds were completely absent) these practices, relationships and objects were on constant display. Most patients who stayed in hospital brought bedding from home as there was a limited supply of hospital sheets and blankets and patients had to negotiate for these with the cleaning staff, who held the key to the laundry cupboard.

Generally only abandoned patients had none of their own bedding. Most patients brought basins and water containers from home which they used for washing in, passing urine and stool in and for storing drinking water, which in some cases had been boiled or treated at home. Patients also brought their own cup, bowl and spoon. The hospital kitchen provided three meals a day but did not supply dishes so patients who did not have these items could not eat hospital food. It was the job of carers to line up at the food trolley and take food to the patients, as well as to feed patients if they could not feed themselves. Finally, it was widely believed among the people with whom I did fieldwork that it was normal for sick people to crave and request certain kinds of food and that family members had a duty to try and meet such requests if they could. In Kagot District Hospital, the rusty bedside cabinets were full of such gifts; Ribena, Lucozade, soda, glucose powder, bread, groundnuts, fruit. These items were a tangible demonstration of love, produced by families in the hope that these special food stuffs might tempt their patients into eating and aid recovery.

I suggest that 'the domestic', in all its local complexity, was made within the hospital via the objects, practices and relationships which I have described in this chapter<sup>135</sup>. True, the hospital was not home, but the domestic can also be viewed not necessarily as tied to a place but primarily as a set of practices. Here, the sick person has moved into hospital but almost all of the care work that would be done at home by family members has moved with them. While certain sets of practices are heavily implicated with particular places (i.e. domestic – home; medical – clinic) the ethnographic evidence here suggests that these practices are not necessarily tied to these places and can equally be made elsewhere. This observation, that the domestic can be made mobile via relationships, practices and objects is at the heart of what I have called spatial practice in this thesis. It is an observation which

<sup>&</sup>lt;sup>135</sup> This is the inverse of the processes described by Michael Brown, who describes bringing the hospital into the home to care for the terminally ill in Canada. (Brown 2003)

escapes the problematic debates around the domestic realm based upon oppositions between the domestic (home/female/nature) and the political (outside/male/culture) or politico-jural (e.g. Comaroff 1987, Strathern 1984, Yanagisako and Collier 1987). It is also takes us away from an approach which has assumed an easy alliance between the domestic and the home (Cieraad 1999). The observation that the domestic is a mobile sphere of practice is also concurrent with the recent movement in medical anthropology towards a shift in understanding of 'the clinic' towards one of a dispersed network of knowledge, intervention and subjectification across multiple social fields rather than as a bounded social space and set of interactions (e.g. Rapp 1999).

This is an approach which can be thought of as building upon Foucault's (1989 [1973]) insight that *The birth of the clinic* was a reorganisation of the way in which it was possible to think about disease and the body, which I suggest opened the way for a kind of thinking about the clinic and clinical practice which was linked but not confined to the physical institution of the clinic. Because Foucault recognised that 'the clinic' was not so much about a particular space as the practices which came together through a way of organising knowledge about the body via a particular way or seeing, or "gaze" as he called it, it has become possible to think about how such practices can be dispersed across different domains of social life.

### How, then, to understand space in this hospital?

In this chapter, I have suggested that care is a useful frame for revealing how the wards of Kagot District Hospital functioned as an institution through a composite of spatial practices involving objects, persons and the built environment. The boundary between the divergent spaces of the medical and familial which existed in this hospital allowed people to comment on and (re)produce particular kinds of authority and obligation to others. These practices were also implicated in creating a sense of institutional space.

Etienne Wenger's (1998) work *Communities of Practice* provides a helpful frame with which to think about the relationship between social practices and institutions. Wenger describes communities of practice as those groups which come together over time to achieve shared enterprises. Such communities of practice can appear to be quite formal and to map institutional boundaries (for example the nurses working at the hospital constitute a community of practice), or less formal, for instance in the case of the caregivers who live at the hospital for varying periods of time. Communities of practice are organic, produced by the mutual engagement of participants, and they are by nature dynamic, shifting and evolving. But the key point here is that even when a community of practice defines itself via an institutional context – for example those who are employed by the hospital – their community of practice involves relationships and activities that blur those same institutional boundaries, "The landscape of practice is ... not congruent with the reified structures of institutional affiliations, divisions, and boundaries. It is not independent of these institutional structures, but neither is it reducible to them" (Wenger 1998: 119).

Wenger's point about boundaries is important because it gets to the heart of the ambiguity of hospital space. Taken together with a reading of space and practice as co-constitutive, it points to the fact that the boundary of the hospital is simultaneously being made and unmade/contested, while at the same time this very boundary is implicated in defining the communities of practice involved in making it. I suggest we might also build upon this idea by thinking about the relationship between the kinds of boundary-making that go on within institutions and how they are related to the creation of perimeter boundaries. Caregivers formed a community of practice which could exist alongside that of hospital staff partly because each community of practice defined itself quite separately and in opposition to the other, but also because these communities of practice had a shared understanding of the location of the proper boundary between the familial and medical body.

There were times when medical staff and hospital processes seemed to undermine the importance of the boundary between the medical and familial by suggesting the greater power of a homogenous medical space which would exclude the familial. Thus, whilst the hospital was dependent upon their work, carers were also structurally excluded by an institutional regime which did not provide them with food or a sleeping place, forcing them to the peripheries of a more powerful medical realm. However, at other times the importance of familial work was emphasised. By way of conclusion, I explore the example of 'abandoned patients' to underline this phenomenon.

Abandoned patients were usually very sick or dying and most often young men, migrant workers living away from their extended family. Those who brought these patients into hospital "ran away" when they were asked to buy a file, or after admission. Nurses did not step in to provide familial care to abandoned patients. These patients might go without food and water, unless another caregiver stepped in to help them. More than on any other occasion, the existence of abandoned patients emphasised the importance of having family members to care for you if you were sick in hospital. The presence of abandoned patients clearly highlighted the limits of medical care and the point where most work was needed to maintain the boundary between the medical and familial. Although they did not help with food, water or bedding, hospital staff endeavoured to make sure medical care was given to abandoned patients and went to great effort to emphasise the limits of their responsibility. On one occasion a nurse wrote in large letters on the file of such a patient, "Continue to give meds until relatives come for this patient", whilst during rounds doctors heavily stressed the need for nurses to continue giving IV fluids to prevent dehydration.

Abandoned patients did not receive good care because it was not possible to construct the domestic around them. I have described in this Chapter how good care on the wards of Kagot District Hospital required, alongside the medical interventions of hospital staff, attention from families which revolved around a number of domestic objects, practices and symbols. Relatedness to others was suggested by the presence of carers, visitors and the networks of support that these people engendered. Abandoned patients had none of these. Abandoned patients also lacked the other main symbols of the domestic: bedding; food; water and domestic objects which enabled washing, eating and defecating.

And yet, although domestic spaces were created around patients on the wards they were not at home, even though care-givers described the work that they did as *kazi ya nyumbani* (Swa. 'work of the home'). It is in the disjuncture between the domesticity and unhomelyness of the wards that the impossibility for abandoned patients to receive proper care can be understood. Compare what is on display in the hospital with what is kept hidden at home. In a typical Luo home the bed is kept out of view. In the case of a single roomed house a curtain is hung from ceiling to floor dividing the room into two areas – one open to visitors and another strictly private, while in wealthier homes the bed is placed in a separate room. The bed is a dangerous object because of its association with sex. Older children should not sleep in or even see their parents' bed.

Other activities which are private and controlled in the home are also made public in the hospital, for example washing the body, defecating and eating. Eating in public particularly is considered a potentially dangerous activity because of the capacity of food to carry the malicious witchcraft of envious others which can make one sick in the stomach. Items purchased in the market are hastily wrapped to keep them hidden from view, particularly if they have been cooked. In the home, the sharing of food is key to the Luo understanding of themselves as an egalitarian people (e.g.Odinga 1967: 7). It is offered generously to visitors and hidden away, often in the bedroom (i.e. in the most private part of the house), when being stored. Recognising that the hospital environment makes

visible activities which are more than domestic, which are private and strictly controlled, helps make sense of why it is that it is only family members who are trusted or able to do it. Female relatives are more appropriate carers not only because they know how to be mothers but because they are more broadly responsible for the management of domestic processes which include not only mothering but the organisation of food and other resources as well as the difficult work of dealing with illness and bereavement (cf. Green 1997). All of this work comes together in the hospital.

To argue that the boundary of an institution and the practices which unfold within in it are in a dialogic relationship to each other is to draw attention to the fact that institutional boundaries are complex, shifting and contested, constructed through multiple, sometimes contradictory, practices. Institutional boundaries are not fixed structures which provide a landscape upon which practice happens, nor do they correlate easily with particular kinds of practice, such as biomedicine. In this Chapter I have argued for a rethinking of hospital space which considers the relationships between different practices, objects and architectural spaces as a composite of spatial practices. Institutional spaces are produced through the conflicts and concurrences of divergent kinds of practices within institutions which are in part shaped by, but can also both emphasise and undermine the importance of a boundary between inside and outside.

## Conclusion: Towards an anthropology of care

"A culture which is chopped up with tools called kinship, economics, politics and religion yields those parts" (Schneider 1984: 198).

As a set of social practices, care might seem too big to be the subject of a single thesis – care is after all the basis of so much human behaviour. Among so many other things, care is a cup of tea made for a neighbour, the naming of a child to satisfy a dead ancestor, a nurse's syringe placed carefully in a patient's arm and a regime of governance. The challenge that I have taken up in this thesis is to refuse to think of such practices as disparate. Instead, I have asked what such practices have in common and probed ways in which this commonality might lead us to critique and reorganise some anthropological organisational practices and categorisations.

I have suggested that part of what makes care useful, analytically, is precisely its slightly enigmatic, slippery nature and the way that it resists attempts at firm, fixed definition. Care, I have argued, is best understood as something that is *done*, as social practice. Practices of care cut across traditional domains of anthropological study; kinship, medical anthropology, the anthropology of government and the state. Practices of care extend beyond the home and the hospital, even while they play a role in enacting the boundary around these institutions. Because practices of care simultaneously cut across, undermine and emphasise boundaries, they provide new opportunities for analysing these boundaries. I argue that it is by following, analysing and describing social practices (like those of care), that as anthropologists we can generate new understandings of divergent social topographies; of what Wenger (1998) calls "the landscape of practice".

In the ethnographic descriptions in this thesis I have illustrated the complex topography of care which has evolved within the context of the HIV epidemic in the small Kenyan town which I refer to as Kagot, and a neighbouring village, Ramira. I have shown how practices of care enact disease and policies to manage it, draw people into relationships which are equally local and global and which extend over time and space, provide a way of understanding the changes that are occurring as people begin to use new HIV therapies such as ARVs, and work to construct the medical and the familial as domains of care inside and outside of the hospital and the home. I have described how practices of care in Kagot are spatial practices, marking the boundaries of responsibility within and between

different domains of care whilst simultaneously enacting these same domains and bringing them into being.

### In praise of shallow ontologies

In this thesis I have drawn upon a concept of practice which is influenced by recent developments in the field of Science and Technology Studies. The best known outcome of this academic tradition is probably its post-humanist approach to studying the social which has considered the agentive qualities of non-humans and the role of such agency in social life. Within this tradition, attention has been turned, for example, to mosquitoes (Mitchell 2002a), scallops (Callon 1986) and door-openers (Johnson 1988)<sup>136</sup> as social actors. From the perspective of the argument I am making here, what is important about this philosophical development is not just that it encourages a change in the way that we think about objects, but more broadly the fact that it is part of a way of researching the social that scholars from this field often refer to as 'ethnographic symmetry' (e.g. Callon 1986, Law 1994: 9-12).

Ethnographic symmetry did (and does) two important things. Firstly, it turned an ethnographic gaze onto areas of social life that had previously not been considered appropriate or available as anthropological or sociological objects (such as scientific practice). Secondly, it argued that everything – people, machines, mosquitoes, scallops and door-openers – can and should be analysed in the same terms. In the words of John Law; the principle of symmetry, "erodes distinctions that are said to be in the nature of things, and instead asks how it is that they got to be that way" (1994: 12).

As a result of this ethnographic expansion, STS approaches to the study of social life have rejected an ontological position where reality is understood as layered, with deeper structures providing a form, or landscape upon which practices are done and instead turned the focus onto the practices which generate and sustain these kinds of ontological orderings (Latour 2005, Latour and Woolgar 1986, Law 1994). It is this latter development which has most influenced the way I have come to think about care as practice.

From this perspective, the key contribution of STS to practice theory is not only that it helps to contract a dichotomy between intention and action (Swidler 2001: 74-6), or between knowing and doing subject (Gherardi 2006, Wenger 1998) or even its radical approach to studying objects and "natures-cultures" (Latour 1993: 103-7). What is important is that this range of literature opens the

<sup>&</sup>lt;sup>136</sup> Bruno Latour uses the pen name Jim Johnson in this article.

possibility to question in a broad sense social science understandings of social life which rely upon a layered, hierarchical notion of reality where certain kinds of practices are seen to exist on the 'surface', while other 'deeper' structures, or identities, influence them or provide a frame within which these surface practices can happen.

One of the goals of this thesis has been to unmask how versions of a layered ontology have often been taken for granted in anthropological analysis. For example, in Chapter 3, I argued that one can think of policy as practice, rather than as providing a background upon which practice can occur as a response or reaction. In Chapter 7 I argued for a post-structuralist understanding of hospital space, suggesting that hospital space should be thought of as a composite of mobile spatial practices rather than through a definition which relies upon an understanding of the physical building and its perimeter boundary as providing an architectural landscape and boundary within and upon which practice happens.

Meanwhile, throughout the thesis, I have tried not simply to reflect upon the associations of care with particular institutions and interventions, or in terms of the context of recent political and economic history of Kenya as though these might provide a background upon which to understand 'local' practices of care. Instead I have tried to think about such couplings as ethnographic concerns to be explained by studying the social practices which create, organise and maintain them.

This ontological shift has not been confined to science studies. Discussing this theoretical development, Mol (2002: 33-9) offers a brief account of the recent history of the term performance in social science, comparing the ontological premise behind Goffman's (1971 [1959]) use of the term in relation to metaphors of the stage, with Judith Butler's (1993) discussion of the performativity of gender. Mol reminds us that Butler recognised that gender identity is not something fixed and given, it is not a deeper truth of the human subject, but something that must be continually performed in changing situations. For Butler there was no 'back-stage' behind performances of gender.

Moreover, while feminists were questioning whether a 'biological' sex might provide a template for a 'cultural' gender (see also Haraway 1991), in other areas of anthropology there were divergent attempts to develop concepts of identity that focused on practice over notions of a fixed inner self, in ways which included developments in kinship studies which began to conceive of relatedness as processual, as something that might perhaps be *done* over time, rather than fixed at birth (e.g. Carsten 1997), to a concern with the ways that we understand people as falling into categories like

'split personality', 'Parisian waiter', or 'pervert' and how the creation of such categories is involved in "making up people" (Hacking 2007 [1986]).

### Towards an anthropology of care

Janet Carsten's work on kinship in Malaysia as an ongoing process of everyday feeding and nurture is evidence that practices of care have been studied in anthropology in ways which have been epistemologically groundbreaking. However, we need to move beyond such work and ask how we can begin to talk more broadly about the 'anthropology of care', in reference to a shared body of literature and set of key concepts or debates. Care work is of central importance in the organisation and management of everyday life, institutions and government. Practices of care differentiate and create relationships, and care opens up interesting possibilities for cross-cultural analysis. Given the importance of care as a social practice across these many domains of life, it is high time that anthropology took care seriously as a topic of study, and anthropologists came together to define the parameters of the anthropology of care.

An anthropology of care already partly exists, but is not articulated as such and is embedded within diverse ethnographic texts. Within kinship studies for example, one could argue that over the last 50 years that the way that anthropologists have reflected upon kinship has consisted of a concurrent shift towards practice and towards care. The seminal text in this literature is *American Kinship* (1980 [1968]) where, David Schneider describes how love and related symbols organise the meaning of different kinds of relationship for American people and simultaneously operate as a "code of contact" (Ibid: 51) for how these relationships should be expressed in practice.

Schneider's twin points, that in American culture, love – as a set of practices - is both an expression of different types of relationships and a guide for 'doing' kinship, has been widely read as beginning a shift from understanding kinship as a state of being or structure, to one of kinship as practice or meaning. This shift is crucial in terms of an anthropology of care. When kinship is seen as much something that is *done* as it is an organising structure, practices of care become paramount, because these are just the kind of practices that *do* kinship. Anthropologists have increasing recognised the centrality of care and nurture within kinship, and Carsten's (1997) work which I mentioned above, can be analysed as part of a group of recent studies which includes important work on gay and lesbian kinship (Borneman 1997, Weston 1997), which document how love and care can create kinship (De Matos Viegos 2003, Gow 1991: 150-78, Klaits 2002, Weismantel 1995).

Elsewhere, to take an example from medical anthropology, Rapp's ground-breaking (1999) book on amniocentesis is an exemplary ethnographic study of practices of care. Rapp follows the trajectories of pre-natal testing as women experience it; beginning with the decision to have (or not to have) amniocentesis. She follows these experiences of testing into consulting rooms and counselling sessions, homes and laboratories. Rapp talks to women undergoing testing; genetic counsellors; disability rights activists; and laboratory technicians about their anxieties and decisions around testing. In the cases of those whose test results show genetic 'abnormalities', Rapp describes their decisions to continue or to terminate pregnancies. All this is infused with Rapp's own experience of amniocentesis and her consequent decision to end a pregnancy with a child suffering from Down syndrome.

Rapp's study follows the practices of amniocenteses into the spaces where social relationships take them. By following trajectories of care, Rapp provides extraordinary insights both into the range of places where amniocentesis matters and the extraordinarily painful decisions that ante-natal testing forces upon some women, and men; whom Rapp describes as "moral pioneers" (Ibid.: 3; 306). What we end up with is both a wide-ranging picture of the meanings and impact of amniocentesis as well as a sense of how the relationships of power that coalesce around 'the clinic' do not remain within a bounded social space but are dispersed across a range of sites through mobile practices.

This ground-breaking work from across different anthropological disciplines constitutes, to my mind, a strong foundation for developing an anthropology of care. Moreover, in this thesis, I have shown that care is not simply analytically useful for anthropology but is also useful more broadly as part of anthropology's comparative project. Following practices of care opens up a prism for understanding what life is like for people, like those I have described in Kagot, who must learn to live with diseases like HIV/AIDS, which require a broad range of caring responses across many different domains of social life, redefining these same social domains in the process of managing disease.

However, whilst we can recognise in this literature potential foundations for an anthropology of care, it is the very fact that the work of Carsten or Rapp is thought of as being first and foremost 'kinship' or 'medical' anthropology which suggests that there is still work to be done in anthropology in terms of thinking about what a discipline based upon the study of social practices, rather than institutions, might look like. It is within such an endeavour that I have situated this thesis.

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