Life Extended: The Intimate Politics of the Antiretroviral Era in Northern Nigeria

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Abstract

For more than thirty years, the HIV pandemic has caused immense harm across sub-Saharan Africa. From the middle of the last decade, however, a treatment revolution has been underway, as effective antiretroviral drugs (ARVs) have become available to millions of ordinary people. This thesis examines the far-reaching consequences of this new reality in Northern Nigeria. It argues that the significance of the ARV era cannot be fully understood simply by monitoring how many patients are receiving treatment, but instead must be explained in terms of the multifaceted changes it has driven in institutions and the lives of HIV positive people.

This study uses ethnographic case studies and participatory methods to understand this new historical moment from 'below'. It provides new empirical perspectives on how the ARV era has profoundly altered the ways in which HIV positive people suffer. The difficulties of daily life when subjected to opportunistic infections, side effects from drugs, and social stigma are compounded by memories of past trauma and fears for an uncertain future.

Previous studies have indicated HIV positive people often form new relationships (e.g. Rhine, 2009), but rarely have these post-HIV relationships been described. This study argues that these new relationships, often distant from conventional family supervision, have a unique character, blending traditional forms with 'modern' ideas about romance.

After a HIV disclosure, incomes and assets (particularly those reliant on family relationships) are often reduced. Along with the cost of treatment (broadly defined to include a range of curative practices), this forces those living with HIV to adapt their livelihood strategies, often using networks of solidarity between positive people.

The process of lobbying for improvements in medical care is also explored. Both doctors and NGOs advocate on behalf of HIV positive people, but do so with strikingly different tactics and results. This has important implications for continuing debates about working 'with the grain' (Crook and Booth, 2011) for development in patrimonial states.

In summary, whilst HIV treatment has saved the lives of millions, inventing drugs and getting them to the people who need them are merely the first steps in alleviating suffering. The thesis traces the most important tasks in securing wellbeing in the ARV era – those pursued by HIV positive people themselves.

Declaration

I hereby declare that this thesis has been composed by me, that the work is my own, and that the work has not been submitted for any other degree or professional qualification.

Pete Kingsley, 2014

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Even by the usual standards of thesis production, writing this document has been a long process. During this project, I have undergone trials with which I could not have come close to coping had I not been supported by an exceptional group of individuals.

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The necessity of changing names for confidentiality's sake means it is impossible to acknowledge directly the many individuals in Kebbi that helped me in ways both mundane and breath-taking during my fieldwork. I can, though, name Carmen McCain, Aminu Bunza, Terwase Tyoban, and Peter Maliki Dondondo for their enormous support.

In this thesis, I describe issues in the lives of HIV positive people in the most analytical and dispassionate way that I know how. This, then, is the only place where I can plainly state how deeply moved and irrevocably changed I have been by witnessing so many acts of grace and compassion in the most difficult of circumstances.

I only have one reference point for understanding such unconditional sacrifice. That is the love my parents have offered me. This thesis is dedicated to them.

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Introduction

I first came to Nigeria with Voluntary Service Overseas (VSO) in 2006, on a placement to work with HIV positive people. I fancied then that I had a burgeoning expertise in HIV – I had previously worked on prevention projects in Tanzania and Ghana, and had for several years been involved in the 'Stop AIDS' campaign in the UK, chairing a student society during my undergraduate study. This latter activism in particular gave me the sense that I knew a thing or two about the major debates – intellectual property issues that kept the cost of life-saving drugs high, interventions from the West that provided assistance but brought with them religious, cultural and political complications, and debates about priorities within and between prevention and treatment.

In time, I got to know my HIV positive clients and colleagues in Kebbi, a state in the far North West of Nigeria. The more I understood of their lives, the more the irrelevance of my hard-won knowledge of global AIDS institutions became apparent. Of course, structural issues of global health and economics shape and constrain the treatment HIV positive people receive. But Kebbi's HIV positive people attempt to preserve their health and better their lives in a far wider and more diverse range of activities than I could have imagined.

The last decade has seen an extraordinary acceleration in the number of Africans who can access HIV treatment. I outline this expansion in statistical and institutional terms in the following chapter – yet such a description tells only one possible story amongst many. Indeed, "many of the contexts, meanings, and consequences of the HIV epidemic are obscured or entirely elided when seen through the conventional lenses of public health programmes" (Hirsch *et al*, 2009:5).

This is a pity, as there are some extraordinary stories to tell. Millions of lives that would once have been sharply curtailed are now being extended, potentially to near-normal lifespans. But often, there is nothing 'near-normal' about these lives.   To thrive, HIV positive people must seek out treatment, pay bills, reconcile with old friends, come to terms with past traumas, and find new romances. They are very often in a unique social position, dragged down by estrangements from family, but buoyed by new alliances with fellow HIV positive people.

Anthropologists, in particular, have begun to pry open important questions about what can be called 'the ARV era'. Smith and Mbakwem's concept of 'life projects' emphasises that "people's social aspirations and trajectories influence their behaviour in ways that are not easily predicted by or understood purely in terms of biomedical priorities"(2007:38).   These life projects are the focus of much of this study. After all, as the stories told in this thesis show, once HIV no longer inevitably confers death, the other major questions of life must be confronted.

Similarly, the novel social forms of the ARV era were anticipated by Vinh-Kim Nguyen, whose descriptions of 'therapeutic citizenship' and 'therapeutic companionship' foreground the importance of the solidarity that HIV positive people find in each other, especially in African settings where "widespread poverty means that neither kinship nor a hollowed-out state can offer guarantees against the vicissitudes of life" (Nguyen, 2005:143).

Informed and inspired by such approaches, this thesis aims to provide a description of the ARV that has the memories, experiences, and indeed the 'life projects' of HIV positive people at its centre. In taking this approach, the aim is not to ignore instrumental questions of how HIV care and support might be provided, but rather to view them afresh from a new perspective. The HIV positive people described in this study are often pre-occupied by issues that have little to do with the formal institutions that provide medical care.

In Chapter One, I outline how the ARV era came into being, and how it finds a particular articulation in Northern Nigeria. In Chapter Two, I outline the methodological strategies I have used to try to tell the stories of HIV treatment from the perspective of those who receive it. I explain why I have preferred ethnographic, biographical, and participatory methods. Chapter Three explores the local political context that sits immediately above HIV positive people in Kebbi state. Here, doctors and international NGOs have taken on the responsibility of lobbying the government on behalf of patients. That only one of these sets of actors succeeds is revealing of how politics works in Kebbi, and has implications for broader debates on doing development by working 'with the grain'.

The subsequent three chapters are the heart of this thesis, and each explores a topic in the lives of HIV positive people. Chapter Four explores what it is to suffer in an era when new medical possibilities sit alongside memories of trauma, present physical and social discomfort, and fears for the future. Chapter Five explores the remarkable romantic lives of HIV positive people, who often must find a new partner, for the good of themselves and for social respectability. Building a post-HIV positive relationship, however, requires inventive ways of combining existing social norms with ideas drawn from elsewhere, raising intriguing questions about love, romance, and modernity in Africa. Finally, Chapter Six explores the personal economics of HIV treatment. Although ARVs themselves are usually available for free, treatment involves other costs, especially when various non-biomedical forms of care are highly valued. Earning the money to pay for these treatments also requires novel strategies when conventional family-support career strategies are unavailable.

The perspectives of HIV positive people point in numerous directions. Many of those profiled have found a capacity for renewal, demonstrated in their newly flourishing businesses or love lives. For others, suffering remains a trap that is difficult to escape – and even the more 'successful' HIV positive people are often haunted by past ordeals and the prospect of an uncertain future.

Taken together, the experiences of these individuals characterise the ARV era: medical technology has extended lives, but when the state and often families are distant, paths toward personal betterment and wellbeing are precarious and uncertain. Whilst HIV positive people are often marginalised, the ARV era itself does not exist apart from ordinary life. What happens even at the edges of society is structured by a core set of conventions regarding political, familial and economic behaviour. Therefore, a close study of the lives of HIV positive people both reveals the particularities of this historical moment, and also provides an unusual vantage point from which to consider broader questions about the state, family, love, and livelihoods in Northern Nigeria.

In exploring these issues, this thesis makes a series of interventions into various theoretical debates within African Studies, development studies, and medical anthropology. The nature of the patrimonial state in Africa has for sometime been a much-discussed topic (e.g. Pitcher *et al*, 2009), not least regarding how development actors must engage such states (Hickey, 2012). Empirical and theoretical reflections on this question are provided, as I argue that while certain forms of patrimonialism block many conventional development strategies, the nature of such political systems also offers other opportunities for engagement.

Contributions are also made to longstanding discussions (primarily within medical anthropology) regarding the nature of suffering for people living with chronic illnesses. I argue that in the ARV era, suffering is often caused and intensified by, and understood within the framework of, a common, powerful experience – family estrangement. I also argue that the support groups, whilst doing much useful work, often use highly stylised presentations of suffering to make sense of their work, internally and externally. These simplified representations, often with strong moralising components, are at odds with the more complicated reality of suffering. This is particularly so for those HIV positive people with mental health issues: even though such conditions appear to be commonplace, few health

providers are well equipped to address them. Explicitly theorising suffering as multi-dimensional and social experience is essential to build towards better systems of care.

The final theoretical contribution relates to methods and epistemology. Given the importance of reflecting the perspectives of HIV positive people, particularly as public health bureaucracies often neglect them, consideration is given to what research are adequate to this task. This thesis uses some participatory methods towards this end, but it also reflects of the limitations, pitfalls, and unpredictability of these techniques. Consideration is given to how some of the epistemological and political benefits of participatory research can be reproduced in a study that combines a number of other (primarily ethnographic) methods.

Chapter One – Origins and features of the ARV era in Nigeria

HIV treatment – a short history of a long struggle

This chapter sets out how the ARV era in Kebbi came to be. It begins by tracing the early development of HIV treatment, its initial usage in the West, and finally, continuing efforts to deliver this life-saving medication to large numbers of people in developing countries.

Then the specific contextual features of HIV treatment in Nigeria in general and Kebbi in particular are discussed. The form of Nigeria's HIV epidemic and the stigmatised nature of the disease are also discussed. I then explore Nigeria's political and social context: decades of impoverishment and political dysfunction have left Nigeria with weak services of many kinds, including health care. There are also various local and historical reasons why formal health care in Kebbi and the North is limited, and sometimes distrusted. Various other forms of alternative medical care are popular and often sought by those with serious illnesses.

HIV positive people are often able to get ARVs from government run and internationally supported clinics and hospitals, but receive little other formal support. Other institutions, therefore, have attempted to fill this need for HIV treatment support. However, they do so with limited resources and consequently uneven results.

Early days

HIV first occurred in humans sometime in the middle of the twentieth century, most likely as an adaption of a primate virus in Africa[1]. In a remarkable coincidence, the early 1980s saw both the first widely observed cases of AIDS symptoms and deaths, and a series of scientific breakthroughs in understanding retroviruses (Vahlne, 2009), the category of virus in which HIV is classified. Following the discovery of retroviruses in 1980, came early

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[1] The exact origin of HIV has been contentious, but the primate hypothesis (e.g. Rambaut *et al*, 2001) is now widely accepted.

descriptions of AIDS cases in 1981, and the isolation of the virus in 1983, which in turn led to the first diagnostic test in 1985 (Vella *et al*, 2012:1231). As one of the leading scientists of the era recalls, this represented "the fastest pace of discovery in medical history from the time of inception of a new disease" (Gallo, 2006:6).

Although it took place in a fearful and impatient climate (Brandt, 1988) in retrospect the search for HIV itself and its treatment appears as a logical and orderly progression, with the first antiretroviral treatment – azidothymidine (AZT) – approved in 1987. This drug was launched amid much excitement, following innovatively expedited trials (Kaitin, 1991). However, the acute limitations of AZT (and similar drugs in the same class) became clearer over time as severe side-effects and declining effectiveness led to poor patient outcomes (Vella *et al*, 2012:1232). Thereafter, a fallow decade of relatively limited improvement in HIV treatment followed.

The beginnings of widespread treatment

However, in the mid-to-late 1990s, a series of new drug classes were developed and approved, along with improved, safer versions of existing drugs (Wynn, *et al,* 2004). At this stage enormous clinical challenges still remained, including working out how to manage side-effects (reduced but still serious), developing protocols for co-infections between HIV and other illnesses, avoiding the emergence of drug resistance, as well as building the clinical structures needed to deliver this on-going treatment (e.g. Lowth, 1999). Nonetheless, a deserved state of optimism had been reached where HIV positive people[2] in the West were being treated effectively for the first time.

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[2] Many organisations use the term 'people living with HIV/AIDS' as a supposedly less stigmatised alternative to 'HIV positive'. The people in this study, however, preferred to use the term 'HIV positive' to describe themselves, and it remains a perfectly adequate definition. In Hausa, AIDS (or, inconsistently, HIV) is translated to as 'kanjamau' (lit. weight-loss, slimming) or euphemistically as 'rashin lafiya' (lit. ill health). However, in Kebbi even in Hausa speakers mostly used 'cutar AIDS' (the AIDS disease).

Expanding this treatment to developing countries, and especially Africa, represented an enormous challenge. In 2000, a course of ARV treatment cost more than US$10,000 per annum, making their "distribution in sub-Saharan Africa…so untenable as to receive no serious consideration" (Marseille, Hofmann, and Khan, 2002:1851). As late as 2003, only 100,000 Africans received HIV treatment, out of 20 million who needed it (WHO, 2006a). As well as the issue of cost, there were serious concerns about the ability of health care systems to deliver complex, toxic, and life-long drug regimens to large numbers of people. Some even feared "antiretroviral anarchy" (Harries *et al,* 2001) in which incorrect drug usage would lead to the rapid emergence of drug-resistant HIV strains.

However, a series of remarkable programmes demonstrated that delivering HIV treatment at scale was indeed possible in developing countries. The Brazilian government's earlier pioneering programme to offer free ARVs in 1996 (Hacker *et al*, 2007; Nunn *et al*, 2007) was an important inspiration. The South African government began to offer ARVs through government clinics and hospitals in 2004 (Bor *et al*, 2013), at around the same time as similar programmes started in Botswana (Heald, 2006).

These national programmes were supported by new international programmes and funding mechanisms, in particular The Global Fund to Fight AIDS, Tuberculosis and Malaria (founded in 2002), and the United States government's President's Emergency Plan for AIDS Relief (PEPFAR, founded in 2003). Whilst these complex programmes have attracted a variety of criticisms and controversies (e.g. Taylor and Harper, 2013 on the Global Fund; or Ingram, 2010 on PEPFAR), the enormous expansion in treatment access they have helped drive is astonishing. The figure of 100,000 Africans accessing HIV treatment in 2003 had grown to 1.3 million by 2006, and to 7.1 million by 2013 (UNAIDS, 2013a).

This historic progress has also largely defied expectations of 'antiretroviral anarchy'. Very good levels of adherence (the extent to which a patient takes

their medication correctly) have been demonstrated in a variety of African settings (e.g. Orrell, 2003; Badri *et al*, 2005).

The success of HIV treatment expansion can be measured in blunt terms in millions of lives extended and billions of pills swallowed. But such statistics must inevitably be silent on the range of contingency, struggle and suffering involved in these extended lives. Neither can they capture the multifaceted ways in which social institutions have had to adapt to this new HIV positive population. It is these aspects of the ARV era that this study aims to address.

HIV in Nigeria

Considering the broad arc of the development and deployment of HIV treatment conceals many crucial differences in national and local contexts. Social and cultural variations and differing levels of political commitment have shaped the birth of the ARV era in important ways. This section highlights what is distinctive about the HIV epidemic in Nigeria generally, and Northern Nigeria specifically.

Present situation

Nigeria has an adult HIV prevalence of 3.7% (UNAIDS, 2012), a similar rate to other West African nations with moderate HIV epidemics, such as Togo (3.4%) and Cameroon (4.6%), but far lower than the East and Southern African nations with the most severe epidemics, such as Botswana (23.4%) or Zambia (12.5%)[3]. Additionally, the size of Nigeria makes its HIV epidemic important in absolute terms. Nigeria has 3.4 million HIV positive people, and 220,000 annual deaths –in each case these figures are the second highest (after South Africa) in the world (CIA World Factbook, 2009).

The HIV epidemic in Nigeria is geographically uneven, as the Southern states and urban populations have the most severe epidemics (NACA, 2012). For adults, the most important method of HIV transmission in Nigeria, and

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[3] These figures are all drawn from the CIA World Factbook (2009).

indeed across sub-Saharan Africa, is heterosexual sex. Studies in West Africa have found that heterosexual sex accounts for around 80% of adult HIV transmission, with sex between men and intravenous drug use (IDU) accounting for most of the remainder, in roughly equal proportions (UNAIDS, 2010). This is in contrast to European and North American epidemics where homosexual sex and IDU have been central drivers (Barnett and Whiteside, 2002).

What has driven Nigeria and Africa's HIV epidemic – and what does this mean for the HIV positive?

A great number of additional different factors have been discussed and weighed as catalysts or drivers of the global AIDS pandemic. These range from medical issues such as the role of unsafe blood transfusions (e.g. Gisselquist *et al*, 2002; Minkin, Potterat and Vachon, 2003; Reid, 2009) to the epidemiological differences of different HIV subtypes (McCutchan, 2006).

More contentious and significant, however, have been discussions regarding the role of particular patterns of sexual behaviour. Whilst heterosexual sex has long been identified as the key driver of the HIV epidemic in Africa, specific behaviour patterns have drawn particular blame as disease drivers (e.g. Pisani *et al*, 2003; Aral, 2004), such as sex work (Morris and Ferguson, 2006, Dunkle *et al*, 2004), sexual violence (Jewkes *et al*, 2010), and mobile or migratory populations (Deane, Parkhurst and Johnston, 2010, Voeten *et al*, 2010).

Perhaps the most important factor – and certainly the most contentiously discussed – is concurrent sexual partnerships. These are partnerships, in which individuals – archetypally a married man who also has a younger girlfriend – have sexual relationships in parallel, which is said to interact with the high infectivity of early-stage HIV to rapidly catalyse transmission (Eaton, Hallett and Garnett, 2011). This has, however, proved a highly controversial hypothesis, from the early days of the HIV crisis (Caldwell *et al*, 1987) to more recent epidemiological disputes (Sawers and Stillwaggon, 2010; Kalichman and Grebler, 2010).

These disputes are themselves part of a broader debate over why Africa has suffered this especially severe, generalised HIV pandemic. One argument emphasises the risky forms of behaviour outlined above as a key cause (Pisani *et al*, 2003), whereas another emphasises that HIV is a 'disease of poverty' – with Alan Whiteside's (2002) version of this latter argument proving particularly influential (see also Freedman and Poku, 2005). These arguments are by no means mutually exclusive, and indeed can be complementary, as poverty is often argued to drive risky behaviour (Guiella and Madise, 2007); a plausible hypothesis, though with mixed empirical validation (eg. le R Booysen. 2004; Madise, Zulu and Ciera, 2007).

The HIV as a 'disease of poverty' argument has been complicated by a series of studies which suggest variously that it may in fact be the wealthy that are most likely to contract HIV (Shelton, Cassell, and Adetunji, 2005; Mishra *et al*, 2007), or that inequality rather than poverty *per se* is the key driver of the epidemic (Piot, Greener, and Russell, 2007; Wabiri and Taffa, 2013). Others still have argued that wealth, inequality and behavioural patterns interact in complicated, dynamic, and geographically variable ways (Parkhurst, 2010), and indeed shape somewhat paradoxical situations whereby "in wealthier regions/countries, individuals with less wealth were more likely to be infected with HIV, whereas in poorer regions/countries, individuals with more wealth were more likely to be infected with HIV" (Fox, 2012: 459).

Other explanations for Africa's uniquely bad HIV epidemic have been proposed – for example, John Iliffe (2006) plausibly argues that the simple historical sequence of the epidemic matters; in contrast to Western nations who were able to identify their national epidemics whilst they were still relatively contained, elsewhere the epidemic had already become well-established. In short, "Africa had the worst epidemic because it had the first epidemic" (Iliffe, 2006: 158). Similarly, Africa's weak health systems in general (Buvé, Kalibala, McIntyre, 2003) and the treatment for sexually transmitted diseases in particular (Fleming and Wasserheit, 1999) are also argued to be crucial accelerating factors.

Out of this morass of overlapping and competing explanations, ordinary people in Kebbi, like so many living in the midst of a HIV epidemic, form opinions about the virus and those who carry it. The multiplicity of explanations, versions of almost all of which I heard debated in living rooms and cafés in Kebbi, means that people tend to place HIV in an ambivalent moral category. HIV is simultaneously a 'disease of poverty' (and therefore its victims worthy of sympathy) and a 'disease of immoral behaviour' (and therefore carriers worthy of contempt). It is a virus that has strong associations with the underprivileged, but it is also understood to strike the wealthy and the decadent.

New drugs may be bringing about a 'normalising' of HIV in terms of its treatment as a medical condition, but the behaviour of the people in this study makes plain that stigma about the disease remains intense. HIV positive people use a multiplicity of strategies to limit public knowledge of their HIV status, or alternatively, deflect moral opprobrium in various ways. As other studies have shown, efforts to reduce stigma (which have been a major component of interventions to tackle HIV) have made only slow progress (Brown, Macintyre, and Trujillo, 2003; and Mahajan *et al*, 2008).

A very common experience of the HIV positive people described in this study is a break of some kind with their family (and sometimes colleagues or friends) driven by this fear and stigma. Social understandings and interpretations of the disease appear to be evolving far more slowly than the medical possibilities for treating it. A defining feature of the ARV era, therefore, is the preponderance of individuals living in circumstances of restored or preserved health, but also a greater or lesser degree of social shame and marginalisation. Describing and understanding the strategies that individuals use to cope with this situation is the subject of much of this thesis.

The evolution of Nigeria's HIV epidemic – belated responses

In 1985 two young women became the first HIV cases diagnosed in Nigeria (Nasidi and Harry, 2006:18). These were early days in the HIV crisis, when the aetiology and methods of transmission were far from clear: it was only in 1985 that the WHO issued a standardised clinical case definition for AIDS (Keou *et al*, 1992). Given this uncertainty and the small number of detected cases, HIV understandably remained a low priority for the rest of the 1980s, with very limited surveillance taking place[4]. In spite of the formation of a National Expert Advisory Committee on AIDS in 1987, replaced by a National AIDS and STDs Control Program in 1988, "the response remained tepid" (Kanki and Adeyi, 2006:8).

Throughout the political turmoil of the 1990s, institutional responses were weak and disjointed, and public awareness also remained limited (Caldwell, Orubuloye, and Caldwell, 1999). A milestone in recognition of the problem came with the death of Fela Kuti, the musician and social critic, in 1994. Kuti's brother, a former Federal Minister of Health, announced that Kuti's death was from AIDS, which according to one doctor sparked "nationwide discussion about the presence and role of HIV/AIDS in Nigerian society" (Wall Street Journal, 2012). Nevertheless, official denial of the scale of the problem "meant [that] neither the federal government nor the state governments committed the needed human and financial resources to prevention and control of HIV infection" (Odotulu, *et al*, 2006:243)

At the return of democracy in 1999, Nigeria began to build better structures to manage its HIV epidemic. This involved the establishment of the National Agency for the Control of AIDS (NACA) along with corresponding state and local government committees in 2001. This was a new era of belated but highly welcome political commitment, better coordination and "a deluge of policy documents that articulate sound strategies, clear targets, and strong action plans" (Odotulu *et al*, 2006:249).

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[4] The first national sentinel survey took place in 1991 (Ministry of Health, 2010:1).

This encouraged confidence in external donors and as part of a more general normalizing of foreign relations, international investment in and support of HIV treatment and prevention greatly expanded (Balogun, 2010). As a result, affordable ARV provision began to be tentatively expanded, with 90,000 enrolled in treatment in 2006, increasing to 300,000 in 2009 (Odafe *et al*, 2012).

One example, however, of the still limited nature of services is in the continued significance of mother-to-child-transmission (MTCT)[5]. Following the adoption in 2011 of a target to eliminate MTCT (UNAIDS, 2011), there have been significant successes in many parts of Africa, with such infections cut by 40-60% in countries such as Kenya, South Africa and Zambia from 2009 to 2012 (UNAIDS, 2012:7). In contrast, however, Nigeria's progress has been weak: despite the success of various individual projects, Nigeria has the largest number of MTCTs in the world, and is one of several countries listed as having made only a 'slow decline' in MTCTs, showing just a 10% reduction from 2009 to 2012 (UNAIDS, 2013b:60).

This alarmingly slow progress, as other poorer countries make greater strides, is of a piece with wider continuing limitations in HIV treatment in Nigeria, which continue to be beset by "weak health systems, poor coordination and insufficient information", and as well as problems arising from "services [that] are largely donor driven with inadequate government supervision" (Ezegbe and Stephenson, 2012:25).

This, then, was the policy environment during this study: relatively well-funded treatment programmes, influenced by global standards of best practice, but filtered through highly dysfunctional health systems, and struggling to carry out the important task of decentralising care out of major

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[5] HIV positive mothers can pass on the virus to their children during pregnancy, childbirth, and breastfeeding. Without preventative measures, HIV is transmitted in 15-45% of cases, but can be reduced to a very low level if treatment is administered to the mother (WHO, 2013a). Tackling MTCT has been a major priority for public health interventions (WHO, 2006b), with efforts to identify HIV positive pregnant mothers and administer ARVs, initially the ARV nevirapine and in recent years more complex therapies (Chi, Stringer, and Moodley, 2013:124).

hospitals, and national programmes dependent on international finance and expertise. For HIV positive people in Kebbi, this often meant that the government provided ARV therapy, but precious little else by way of support.

Life in Nigeria

As the above description suggests, HIV programmes and understanding of HIV do not evolve in a social and political vacuum[6]. The characteristics of Nigeria's political institutions have been extremely important in shaping the characteristics of Nigeria's ARV era. Therefore, this section outlines a number of significant features in Nigeria's recent social and political history. Nigeria has an infamous reputation for widespread corruption, bad governance, and for squandering its considerable oil wealth. These issues, along with a stuttering and partial return to democracy are summarised here, as they are a backdrop to the lives of all of those discussed in this study. In particular, the characteristics of Nigeria's distinctive political institutions are of special relevance to the description of political advocacy in Chapter Three.

The politics of Nigeria - recent history and prospects

"Nigeria has no business with poverty" said Olusegun Obasanjo, accepting his party's presidential nomination in February 1999[7]. His comments reflect a common sentiment that Africa's most populous nation should have long ago escaped mass poverty – not least because of its significant oil reserves[8]. Three months later, Obansanjo – reprising a previous stint as Head of State in the late 1970s – became the first democratically-elected President in sixteen years.

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[6] Parts of this section have been published in revised form as (Kingsley, 2013a).

[7] 'Let's Rebuild Together' (Obasanjo, 1999).

[8] Estimates of the oil reserves area are subject to considerable uncertainty. Oil exports comprise more than one-third of Nigeria's GDP, and one estimate suggests that at the current rate of extraction its reserves will be exhausted in around 45 years (Esfahani, Mohaddes, and Peseran, 2012:10).

Many hoped for a fresh start. Since independence from the British in 1960, a string of military dictatorships and weak civilian governments (see Falola and Heaton, 2008, for an overview) left Nigeria directionless, impoverished, and beset by the particularly pervasive form of corruption for which Nigeria is famous (the nature of corruption and patrimonialism is explored in Chapter Three).

Yet the post-1999 democratic era has perhaps been the keenest disappointment of all. Accounts of Nigeria tend to emphasise what could be rather than what is – a sleeping giant that never wakes, a potential regional superpower forever postponed, and a hypothetical African powerhouse always just a few years away.

By 1999, a dangerous set of political and demographic processes were already in motion that have locked Nigeria into a pattern of political failure and economic stagnation. Radical changes remain necessary to move Nigeria on from 'the business of poverty'.

Political failure and the new sectarianism

Nigeria is divided into a predominantly Muslim North and predominantly Christian South – though this is only a rough distinction as large minorities live in each region. Religious tensions have ebbed and flowed throughout Nigerian history (Sklar, 2002). Public life often seems dominated by a game of quotas. Getting the correct balance of region, religion, language and ethnicity in any public body – from the Federal cabinet to television newsreaders – is something of a national obsession. There is even a 'Federal Character Commission', established in 1996, with the responsibility of ensuring that public sector bodies are neither dominated by nor excluded by particular groups (Mustapha, 2007).

Such quotas are largely a function of a clientelist state that disburses oil wealth through political offices. Nigeria is often described as having the

world's most expensive legislature[9], each Senator or Representative a nobleman dispensing patronage in their own domain, a pattern mirrored at all levels of government (see the essays in Adebanwi and Obadare, 2010 for various perspectives).

A political system that emphasises building support amongst and looking after one's 'own people' has consistently undercut attempts at national progress. It has also intensified religious and ethnic resentment, expressed in acts as mundane as the restriction of university scholarships to the 'right' people, for instance, and as horrifying as mass violence.

The most violent manifestation of this new sectarianism is the rise of the Islamic militant group Boko Haram[10]. The group, founded in 2001, rose from obscurity to deadly prominence in 2009 in a string of gun and bomb attacks that have killed more than a thousand people. Indeed, the Nigerian government is now able to exercise only tenuous control of the North-East, Boko Haram's heartland, as the group "has managed to attract considerable popular support…despite harsh police and army repression" (Loimeier, 2012: 138).

The precise nature of Boko Haram's ideology, strategy, leadership, and possible connections with international Jihadist networks are difficult to pin down. Their attacks have been a mixed bag of ideologically driven assaults against the Nigerian state, reprisals against heavy-handed security forces, and opportunistic criminality (including bank robberies). Since its rise to prominence, the group has received considerable academic attention, much of it speculative and based on little empirical observation – (see Adesoji, 2011; Walker, 2012; and Thomson, 2011, for welcome exceptions).

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[9] See for instance, The Economist, 15th 2013.

[10] A colloquial nickname – the group itself prefers the title *'Jama'atu Ahlus-Sunnah Lidda'Awati Wal Jihad'* which translates as, 'Followers of the Prophet involved in Call to Islam and Religious Struggle'.

What is clear, however, is that they have both responded to, and in turn catalysed an increasingly lethal atmosphere of sectarian tension – one that feeds in part on the disparity between an extremely poor North and a somewhat less impoverished South.

In addition to Boko Haram's destructive activities, political violence along ethnic and religious lines has taken on a steady drumbeat: a village attacked here, and church or mosque bombed in reprisal there. This is particularly so in the mixed middle belt, where competition for land and government resources is fierce. Meanwhile, a low-level form of civil war persists in the Delta region in the South, as the state and local militias contest the oil fields.

A staple of political discussions in Nigeria is to wonder if splitting the country is the only answer (Muammar Gaddafi's suggestion to partition along North-South lines provoked considerable debate – see BBC News, 2010). Yet the consensus view appears to be that people and institutions are far too intricately intertwined for this to be more than a distant pipedream.

Nigerians must live with one another if only as quarrellers handcuffed together, whilst the patriotic pluralism of Obasanjo's 1999 speech, of joining "hands together to rededicate ourselves to the service of our country and to the unity of our people" rings ever more hollow.

Unsolved problems

As well as fuelling ethnic resentment, Nigeria's political institutions have been so preoccupied with managing their patronage networks that national crises have gone unaddressed. Through their mass sclerosis, an intimidating set of challenges has accumulated.

Chief amongst them is a twin crisis of demography and education. High birth rates, rising life expectancy and falling infant mortality has seen Nigeria's population explode from 123 million in 2000 to 170 million in 2012, and a projected 240 million by 2050 (United Nations, 2013).

Some have argued that this may eventually pay off as a handsome 'demographic dividend', as falling birth rates mean a greater proportion of Nigerians join the workforce relative to the old and young they support. For instance, the (Nigerian) managing director of the World Bank Ngozi Okonjo-Iweala has argued that, "one of the greatest untapped growth drivers in Nigeria's economy is our youth population" (quoted in Bloom and Canning, 2011:6). Others, such as Kate Meagher (2013a), have contended that such arguments – as with the 'Africa Rising' trope fancifully proposed by The Economist (2011) – will prove farfetched while ever job creation remains low.

In either case equipping this current bulge of young people for skilled and semi-skilled employment is a formidable task for Nigeria's creaking education system. Various statistical measures suggest a dismal picture – Nigeria has 10.5 million out-of-school children, more than any other country (UNESCO, 2012:61), with only 46% of children enrolled in secondary school (*ibid.*:370), and 35 million illiterate adults (*ibid*:92). As elite Nigerian families send their sons and daughters to study abroad[11] or to sealed-off private institutions within Nigeria, state schools, colleges and universities are seen as decidedly inferior destinations.

Finding productive employment for an inadequately educated generation poses a huge challenge for Nigeria. Oil revenues supply the bulk of Nigeria's wealth, but the industry employs only a tiny sliver of the population. Longstanding industries in the North, undercut by Asian competition, have collapsed, for instance, "the number of textile and garment firms [fell] from 175 in the mid-1990s to fewer than 25 in 2010, with a loss of over 110,000 jobs" (Meagher, 2013b:171). Large-scale manufacturing continues to prove elusive, with the president of the Manufacturers Association of Nigeria reporting that manufacturing employment declined from 2.75m in 2001 to 0.96m in 2010 (This Day, 2011) leaving a largely underdeveloped agricultural sector as by far the biggest employer.

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[11] The British Council predicted that by 2015, 30,000 Nigerians will study at British Universities alone (THES, 2008).

Perhaps the greatest inhibitor of manufacturing and enterprise – more so even than endemic violence and graft – is the woeful state of Nigeria's physical infrastructure. That three-quarters of households use firewood as fuel (Oseni, 2012) is extraordinary given Nigeria's hydrocarbon wealth. Potholed roads and intermittent, expensive electricity are daily sources of frustration and wearied humour, and more importantly, a constant retardant on commerce of almost every kind. Mercifully, mobile phone costs and internet speeds – for many years worse than other African markets – have improved in the last few years (GSMA, 2012).

Coping and distracting

In this unpromising political and economic climate, Nigerians must go about their business. Flexible livelihood strategies are a means of getting by – many Nigerians divide their time between multiple income sources, blending informal trading, farm small-holdings and casual labour with whatever scarce and underpaid formal employment can be found (see Meagher, 2010, and the discussion of informal livelihoods in Chapter 6).

Saving up to send a favoured son or daughter to study and work abroad has proved a highly successful strategy, at least for many of Nigeria's more comfortable families. Professionals of Nigerian origin prosper across the West, sending vast sums back to the homeland in remittances.

Meanwhile, a diverse range of cultural industries flourish. Exuberant Nollywood films find vast audiences both at home and across Africa. Readers seek out Nigerian fiction in a range of formats – whether mass-market, inexpensive 'market literature' for the gossip and scandal hungry masses, or literary fiction for global cultural elites.

Promise for the future

With so much disappointment in the past, and so many challenges in the present, optimistic predictions are difficult to justify. Nonetheless, some of Nigeria's challenges are more readily solvable than others.

President Goodluck Jonathan is an accidental leader elevated from the vice-presidency following the death of his predecessor. Despite his re-election in 2011, he is a relatively weak figure. Unlike his predecessor Obansanjo, he has proven to be incapable of suppressing sectional violence.

Yet the Federal security forces have been used to keep a lid on violence before, and they could be so used again. Improving Nigeria's roads, and power generation and transmission represent significant but by no means insurmountable technical challenges. Concentrated and judicious interventions in these areas could generate significant momentum and confidence towards tackling longer-standing problems such as those in the education system. Similarly, the agricultural sector is ripe for investment and efficiency gains (Akinola, Issa, and Sanni, 2013).

Nigeria is undergoing a twin religious revolution, with a form of Sharia law since 1999 in the North, and a rapid growth in Pentecostal Christianity. These trends are often received with alarm amongst Western liberals – with periodic (but as yet unfulfilled) threats to stone to death adulterous women, or various legislative attempts to crack down on short skirts and homosexuals.

But perhaps these religious transitions hold promise. It is fanciful to imagine a current generation of reactionary Muslims and self-enriching prosperity preachers to take up this mantle. But as the youth bulge comes of age, they are connected by technology as never before, drawing their own conclusions from Islamic and Christian theologies of social justice. New tools for imagining a better Nigeria and holding its leaders to account may become possible, and recent outrage at Pentecostal pastors with private jets[12] could be a sign of things to come.

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[12] This story provoked much comment in Nigeria, and even in the international press. As Forbes (2011) summarises: "David Oyedepo, a Nigerian cleric generally believed to be Africa's wealthiest gospel preacher, acquired a Gulfstream V jet for US$30 million. Oyedepo, who presides over the Winners Chapel, one of Africa's

Nigeria's burgeoning middle class is a more significant sector of society than in most of Sub-Saharan Africa, and is also poised to demand better of its leaders. The 'Occupy Nigeria' demonstration of early 2012 began as protest at the removal of subsidies on fuel (seen as one of the few widespread benefits dispensed by the state). Yet it gained broader resonance as an example of the urban middle classes acting on their disaffection more effectively and coherently. Similarly, a whole series of strikes by professionals such as doctors and university lecturers have been highly disruptive, but have nevertheless embarrassed politicians into various reforms.

A closing window of opportunity

As Nigeria's oil reserves run out so does its room for manoeuvre. If it invests its remaining petro-dividends at least somewhat effectively – particularly in infrastructure, and if some respite from violence can be found – work towards making Nigeria competitive, and towards building effective governing institutions could begin.

But such reforms are by no means assured, and in any case, they are preconditions for, not guarantees of, a Nigerian revival. It remains to be seen whether Nigerians can do what Obasanjo (1999) promised but could not deliver and "re-establish the traditions and structures of good governance that have broken down". For the purposes of this study, these political features imply that Nigeria's health care system is likely to continue to be limited and patchy, a situation that is particularly bad in the North.

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largest churches, now owns a private collection of four aircraft. In addition to his latest acquisition, he previously owned two Gulfstream planes and a Bombardier Challenger Aircraft. He is also reportedly creating a private hanger to accommodate his flying toys."

Life in the North

As suggested above, Nigeria is in many ways divided by region, and various aspects of Northern Nigeria make it a distinctive context for the expansion of HIV treatment. The following section explores these characteristics.

When discussed by foreigners or Southerners in the fashionable parts of Lagos or Abuja, Northern Nigeria primarily represents two things: poverty and Islam. To take each in turn – broad statistical measures like GDP suggest Nigeria is a lower-middle income country, yet the poverty in the North is similar to the poorest regions in Africa. Health and education statistics have more in common with the highly impoverished state of Niger – over the Northern border – than regions in the South of Nigeria. For instance, 53% of children in the North-West sub-region are classified as stunted (a symptom of malnutrition), and a mere 6% have received all the basic vaccinations (NPC and ICF Macro, 2009). In education, a study in Kano (elsewhere in the North) of teachers – let alone the pupils – judged 78% to have 'limited' reading comprehension (ESSPIN, 2010).

Islam is a distinctive contextual feature for this study too: as Tocco points out, Northern Nigeria "has one of the highest levels of HIV prevalence among societies that are predominantly Muslim" (2010:385). Although in the North, predominantly (Sunni) Muslim, there are significant Christian minorities, particularly in the cities and larger towns. It has sometimes been suggested that behavioural constraints might reduce the vulnerability of Islamic populations (Gray, 2004), but there is no reliable data however to suggest whether Christians or Muslims are worst affected in Kebbi state[13] or the North in general.

As well as the region's severe poverty, the shift towards more conservative forms of Islam has alarmed Western donors. Ever since twelve Northern

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[13] Nigeria is divided into 36 states, which are in turn sub-divided into Local Government Areas. All three levels of government are involved in HIV treatment in various ways, but in this study state-level facilities were especially important.

states declared a version of Sharia Law in 1999, as mentioned above, there has been considerable concern that the region "could become an incubating site for militant Islam and possibly terrorism" (Obi, 2006: 99). With Boko Haram apparently fulfilling this prophecy, addressing poverty in the region is seen as a major security as well as development priority. For instance, a Department for International Development document argues "progress in northern Nigeria will help regional stability across the Sahel, where the potential for terrorism is a concern" (DFID, 2009: 3).

Life in Kebbi

The particular setting of this study is Kebbi, a geographically expansive state in the North West region. Kebbi is a relatively new state, created out of the old Sokoto state in 1991. It has a population of 3.2 million, and a predominantly agricultural economy.

The location of Kebbi state (map adapted from First Bank).

The process of establishing the new state's government was highly disruptive, requiring the establishment of a whole range of new bureaucracies, and the relocation of 70% of the previously Sokoto-based staff responsible for administering Kebbi to the new capital, Birnin Kebbi (Alapiki, 2005: 63). Despite the considerable challenges in effectively governing this new, poor, and sparsely populated region, many interviewees in this research emphasized that 'Birnin Kebbi is a small town'. That is to say, a closely connected elite dominates senior positions, and whilst formal bureaucracies are often dysfunctional, those with grievances or requests – at very least the heads of well-known families in good-standing – are usually able to secure an audience with the relevant official relatively quickly. The interpersonal quality of governance in Kebbi state and its effects have political consequences for Chapter Three, which describes political lobbying in the state.

The severity of the HIV epidemic in Kebbi state is a matter of some dispute. In national surveys between 1999 and 2008, Kebbi reported prevalence rates between 2.5% and 4%[14]. The most recent survey however (based on data collected in 2010) suggests Kebbi has a rate of just 1%, the lowest in Nigeria (Ministry of Health, 2010:45). Several doctors pointed out that these rates vary considerable from survey to survey with no obvious cause, suggesting limitations in the survey methods[15]. Nevertheless, it can be assumed that Kebbi has, by Nigerian standards, a low to moderate HIV epidemic, with HIV populations ranging from anywhere between 32,000 and 128,000 (to extrapolate from the above prevalence rates).

Medicine in the North

When these HIV positive people – however numerous they may be – seek care, they do so from medical institutions, formal or otherwise, with distinctive histories and characteristics. One branch of Nigeria's medical

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[14] National sero-prevalence surveys, based on data drawn from antenatal screening, report the following results: 3.7% (1999), 4.0% (2001), 2.5% (2003), 4% (2005), 2.9% (2008) (Ministry of Health, 2010:45).

[15] As an official in another state with a much higher prevalence complained: "We just want to make a point that these figures are just not right." (This Day, 2013).

history began as the colonial government tried to transplant aspects of the British medical system to Nigeria (Schräm, 1971). British doctors were hired, and later Nigerians were sent to the UK for training. Hospitals and training facilities were built, establishing a modern biomedical system in Nigeria (Ityavyar, 1987; Ibrahim, 2007).

This British-inspired system was understood through a particular lens of historical experience. Colonial hospitals at first treated only British personnel, until their mandate was gradually extended to include key local collaborators such as officials, policemen and military servicemen (Pearce, 1980:93). Another key development was that an emphasis was placed on doctors and major urban hospitals (ibid.:92) as opposed to public health, rural clinics, or general practitioners.

Ordinary Nigerians in the late colonial period, therefore often looked upon hospitals and the treatment they offered (or refused) in a particular political and spatial way, associating them with privilege, exclusion and a particular way of governing (Sadowsky, 1999). As independence came in 1960, the direct memory of these times is well within reach of older Nigerians.

It worth noting several other broader points about health in the colonial era. The first is that health was a central concern for the imperial project. The success of the empire directly depended on applying science to successfully manage illness in Africa, a place thought of "as a repository of death, disease and degeneration" (Vaughan, 1991:2). Meanwhile, many of the most serious epidemics – especially influenza – were a direct result of the new patterns of domestic disruption and trans-continental travel to which colonialism was central (e.g. Arnold, 1986; and Lyons, 2002). That present day global health activists complain that global health research priorities are skewed away from the needs of poor countries is in a sense an ironic reversal from the colonial era, as the need to cure tropical illnesses drove much Western medical innovation, for instance in the invention of antibiotics (Akyeampong, 2006).

The ties between the colonial project and hospitals foreshadowed subsequent era relations, in which power and medicine continue to be articulated in spatial ways in Nigeria. As part of their government contracts, doctors are often provided with homes (Alubo, 1986; Pearce, 1988) – an attractive perk in Nigeria's bigger cities that are often starved of decent housing. That doctors often live in designated, privileged places reinforces their prestige, power, and the sense that they are somehow a 'special case'. This exceptional status is echoed in Alubo's (1986) account of industrial action taken by doctors in the 1980s, in which they were consistently successful in bargaining with the government (a pattern explored further in Chapter Three).

In short, this new system of biomedicine was formal, centralised, urban, hospital-based and, at least for a time, considered foreign. However, Western derived biomedicine is merely one of several traditions of health care in Northern Nigeria. A panoply of Islamic, Christian, and 'traditional' healers offer consultations and treatments of various kinds. As Chapter Six explores, HIV positive people must navigate this confusing, plural context to secure treatment.

The popularity of religious and traditional medicine can be read in part as a lack of confidence in formal health care. Certainly, health care in Nigeria is often very poor. Akyeampong argues that "solid health care systems are the products of strong economies" (2006:202), and in spite of the massive wealth generated in the oil-rich Delta region, chronic underinvestment in public services has long been the Nigerian norm (Falola and Heaton, 2008: Chapter 8). Given this pattern of elite capture of wealth and inadequate public health provision, it is unsurprising that the standard statistical indicators of a population's health remain so dismal – average life expectancy is only 52 (UNICEF, n.d). Poor transport infrastructures (Ayeni e*t al*, 1987), community conflict and ethnic/religious violence (Gruber and Caffrey, 2005), and a culture of patronage and corruption (Smith, 2007) all seriously hampered Nigerian health care.

The fallibility and limitations of biomedicine is particularly exposed by diseases that are difficult to treat. HIV/AIDS has long been a paradigmatic example of the limits of biomedical science. After all, whilst this study documents an exciting era of expanding treatment (albeit through complex, expensive and toxic therapy), HIV remains incurable more than three decades after its discovery. Despite major, well-funded efforts, neither a cure nor a vaccine for HIV is a likely prospect in the short or medium term (Chun, 2012; Burton *et al*, 2012).

Given that modern biomedicine's limits are exposed by an epidemic such as HIV, and the longstanding inferior medical provision in a region (Pearce, 1980), it is understandable that the elite and the public in Northern Nigeria should have major reservations about their health care services. The concerns found expression in 2003, when several Northern politicians and religious leaders opposed a World Health Organisation led polio vaccination programme, with many citing fears that the project was a Western conspiracy to render an Islamic population infertile (Renne, 2006; Yahya, 2007).

This crisis embodied several political fault-lines, including a suspicion of the West and a move for greater regional power. Yet, as Yahya (2007, see also Osazuwa-Peters, 2011) shows, the incident also represented frustration with a public health strategy that seemed more attuned to donor priorities than local needs, and a concern that previous incidents where Western pharmaceutical companies had caused illness through unethically executed drug trials (notably by Pfizer in Kano in 1996 – see Lenzer, 2007) would be repeated. This accords with Kaler's (2009) meta-analysis of various public health conspiracy theories, in which rumours function as cultural metaphors for wider anxieties about group safety and survival (see also, White 2000).

In summary, the medical context in Northern Nigeria is highly politicised terrain. Doctors and hospitals are vital portals to life-saving care for many people described in this study, and retain considerable prestige as political actors. But they are also profoundly limited in their ability to provide, and

occupy a precarious social and cultural position – simultaneously senior and respected members of the community, but also representatives of an untrusted and failing system.

Above all, perhaps, doctors are distant figures for many HIV positive people. Consultations with HIV patients in hospitals, including many I witnessed as a volunteer, were typically brief and perfunctory, inevitably so given the limited number of doctors. This meant that if crucial tasks of treatment support were to be performed, the responsibility would fall to other individuals and groups.

The Kebbi Alliance for Positive People

The letterbox outside KAPOP's main office.

The starting point and setting for much of this study is The Kebbi Alliance for Positive People (KAPOP). KAPOP was founded in 2001 around the same time as a number of similar support groups for HIV positive people[16].

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[16] A directory of organisations (Federal Ministry of Women's Affairs and Social Development, 2008) lists several dozen such organisations, both national and state-

KAPOP's growth came, particularly from 2004 onwards, when donors were beginning to see support groups as a crucial tool for expanding care and enabling HIV positive people themselves to take a key role managing their own care, and that of their peers.

GHAIN[17] (a PEPFAR funded project) alone established 119 facility support groups (that is, those based in hospitals or clinics) and 33 community support groups in Nigeria, with a cumulative membership of more that 115,000 (GHAIN, 2011:11). Much was expected of such groups - GHAIN reports the following benefits of such groups:

- *"Opportunity for sharing experience among members*
- *Opportunity to learn more on how to live positively with HIV*
- *It encourages social interaction and integration*
- *Opportunity to know more about HIV/AIDS, opportunistic infections, and their prevention and management*
- *Reduction of loneliness, stigma, and discrimination*
- *Created avenue for support of the group by other interested individuals and bodies*
- *Affords members the opportunity to learn more about; nutrition, succession planning, income generating activities etc*
- *Affords members the opportunity for forming cooperative societies that can assist economic strengthening of group members*
- *It affords members opportunity to overcome challenges of living with HIV."* (adapted from *ibid*: 11-12)

The breadth of this list is revealing: under the open-ended descriptions of 'living positively', 'holistic treatment', and 'care and support', support groups were conceived as a catch-all supplement to the health care services

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based, that describe themselves as working with HIV positive people, or HIV-related orphans. For instance, the 'Positive Development Foundation' in Cross River state, the 'Positive Care Foundation' in Bayelsa, and 'Help Encourage Persons with HIV/AIDS' in Edo state (all founded in 2003).

[17] The Global HIV/AIDS Initiative in Nigeria.

which, as described above, were typically able to provide ARVs and little else. That so much was expected of a largely untried model reflects the understandably hurried expansion of HIV treatment, in which "care and support programmes are often an afterthought, do not realistically take into account the contributions of women and families, and are not sufficiently costed and budgeted" (UNAIDS, 2007:6).

KAPOP's development exemplifies this somewhat experimental and haphazard approach to treatment support. At the time I first arrived in 2006, KAPOP was receiving semi-regular grants, primarily from international NGOs. These grants were typically small (between US$200-1500), and theoretically mandated for specific projects, such as the distribution of food to widows with children, or holding a workshop of good adherence. Nevertheless, some of this funding appeared to be fungible, and was enough to allow KAPOP to maintain and equip a small property in the centre of Birnin Kebbi. This comprised of an office for the coordinator, and a sitting room in which members could visit, speak to another HIV positive person, or simply rest in the heat of the day.

KAPOP often described itself in official communications as having four staff, eight 'trained volunteers', and around 50 members – all of whom were HIV positive. This both overstates and understates KAPOP's size. Throughout 2006-2012, KAPOP was unable to pay a regular salary to any of its staff, which was led by a co-ordinator, and also included a chairman, secretary, and an accountant. Although KAPOP's leadership all had full time jobs elsewhere, they nonetheless visited the KAPOP office most days. A second tier of 'volunteers', were occasionally sent to attend courses to develop counselling or 'positive living' skills, and could be called on to carry out various tasks.

The informal and transient nature of KAPOP's membership made its size difficult to gauge. Hospital doctors and others familiar with KAPOP would often refer HIV positive people to KAPOP, often immediately after a diagnosis. Many individuals would visit only once or twice, whilst others

stayed in touch. Only around 30 people were regular members, in the sense of either visiting the office occasionally or attending some of KAPOP's monthly general meetings. However, between the leadership and volunteers of KAPOP, a much greater number of HIV positive people was known at any one time – perhaps as many as 200 people. Whilst most came from the city of Birnin Kebbi, a significant number of contacts were maintained in rural areas and small towns throughout the state. KAPOP was predominantly female – usually around 70-80% of the total membership.

Like many such organisations, KAPOP described itself as having a broad mandate ranging from caring for orphans to HIV prevention. KAPOP's primary activities, however, were quite narrowly restricted to treatment support. That is, to counsel (especially newly diagnosed) HIV positive people, to advise on issues such as treatment adherence and healthy eating, to provide practical support in accessing drugs (such as transporting them to the more distant towns), and providing support for members.

In many ways, the defining feature of KAPOP's work was unevenness. Its portfolio of activities would dramatically expand and contract depending on the availability of its leadership and – especially – the availability of funds. Occasionally, the KAPOP office was closed for several weeks at a time, and most of the senior members had either travelled away or could not be contacted. At other times, KAPOP engaged in sustained periods of intense, almost frenetic activity as a steady flow of visitors came and volunteers travelled on a daily basis to other towns to deliver drugs and training.

The patchy quality of KAPOP's work extended to other areas. Perhaps inevitably, the overstretched staff with little training offered counselling and advice of highly variable quality. This thesis documents some of the ways KAPOP is present or absent in the lives of HIV positive people, or acts with compassion or insensitivity. But it does not do so with the intention of judging KAPOP or its staff. Rather, it is to explore how HIV positive people must continue their lives in the context of support that – like KAPOP – is often uneven and incomplete.

Summary

The provision of HIV treatment in Africa, whilst patchy and imperfect, is nonetheless remarkable in the scale and speed with which it has been expanded. A range of research and health care institutions have helped to extend the lives of millions of HIV positive people. However, in places such as Nigeria, medical care (amongst other basic services) remains weak. Thus, the ARV era is unfolding in a context where the state (supported by international institutions) is able to dispense live-saving drugs, but offer very little else by way of treatment support. The nature of Nigeria's political and social problems means that this minimal level of state provision is likely to continue.

Furthermore, the particular history of HIV means that it is a profoundly stigmatised illness. Often, as the case studies in this thesis discuss, this stigma is enough to break-up families, with far-reaching consequences.

A set of institutions has emerged to tackle these issues. Support groups such as KAPOP are loosely connected to health care providers, and offer support to HIV positive people making difficult adjustments in their lives. KAPOP and others like it, however, are severely lacking in expertise and resources, and thus can only offer a partial and uneven level of care. As with so many other areas of Nigeria's impoverished and dysfunctional society, those providing and receiving care do so in institutional contexts filled with gaps, uncertainties, and absences. This means in turn that making do, improvisation and adaptation are defining features of Nigeria's ARV era.

Chapter Two - Research decisions and approaches – telling stories from Kebbi

This chapter explains the strategies used and decisions made during this research project. As Silverman notes, methodology chapters are often "desperately boring" (2004:305) affairs that appear to exist "for purely formal purposes" *(ibid:* 306). I hope to avoid such a mechanical, defensive account of this project. This is not simply an attempt to be merciful to the reader, but instead recognises the value of frankly discussing the limitations and mistakes that become apparent during a research project.

I hope, then, to outline the choices I have made in pursuit of a satisfactory research project, but also to highlight those areas in which the research process raised troubling questions. This chapter is in three parts. In the first, I provide a short narrative account of how I planned and conducted my research, and the assumptions that informed the decisions I made.

In the second part, I note with concern the similarities between the participatory research techniques (used in part of my data collection) and participatory development interventions. Such development projects, including those described in this research, often struggle to fulfil their stated aims of empowering poor people, and indeed can become disempowering and oppressive. Therefore, I consider how participatory research might be subject to similar risks.

In the third and final section, I discuss the complications and difficulties involved in researching people who are suffering. Mindful of the power relationships involved in research, especially in developing countries, I explore strategies to minimise any risk of causing further harm, but also to consider the potential for research to be a positive, unburdening process.

A narrative of the research project

The goal of this research project is to describe the unfolding ARV era from the perspective of HIV positive people. In the preceding chapter, I have set

out what is unique about this historical moment, in terms of the trajectories of both HIV treatment and local and Nigerian society. This literature suffers from a relative silence of the voices of HIV positive people. Collecting these views is not merely a goal for its own sake, but is crucial to understanding the contours and contingencies of the first era of mass HIV treatment.

What remains is to select the methods that are most suited to this task. The central constraint of research of this kind is the hidden nature of the HIV positive population. Whilst some HIV positive people make their status publically known, the vast majority will go to considerable lengths to conceal it (Greeff *et al*, 2008).

A large part of my enthusiasm for beginning this project was recognition that my prior voluntary work had given me a rare level of access to a HIV positive population in Africa, and one that is especially unusual outside of the East and Southern African contexts that have seen the most HIV-focussed research. I returned to Nigeria with the numbers of around thirty HIV positive people in my phone, many of whom I had kept in touch with. This was an asset beyond price. I also had moderate working knowledge of many of the issues that preoccupied HIV positive people and practical experience of meeting with them in an inconspicuous manner. A basic facility in Pidgin English and Hausa (the latter progressed to an intermediate conversational level over the course of the project) were also valuable.

In 2010, I made my visit to Nigeria, where I divided my time between Hausa language learning at Bayero University in Kano and preliminary scoping visits to Birnin Kebbi. In subsequent trips, I rented a flat in Birnin Kebbi, and stayed there for a total of fourteen months. I spent most of my time Birnin Kebbi, but also visited various smaller towns in the state. I reconnected with many of my old acquaintances in KAPOP and beyond, and introduced myself to the local authorities[18].

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[18] There was no formal process of obtaining research permission in Birnin Kebbi, though I did discuss my research aims and activities with officials at the Ministry of Health, the hospitals I visited, immigration officials, and the police. Many of these

Schedule of PhD work	
September 2006 – August 2007	(prior to doctoral study) Placement with KAPOP in Birnin Kebbi through Voluntary Service Overseas
September 2008 - December 2009	Desk study in Edinburgh
January 2010 - May 2010	Language learning in Kano, preliminary visits to Kebbi
June 2010 – September 2010	Desk study in Edinburgh
October 2010 - March 2011	First period of field work in Kebbi
April 2011 – August 2011	Desk study in Edinburgh
September 2011 - April 2012	Second period of field work in Kebbi
May 2012 - January 2014	Writing up

The task, then, was to convert a promising set of assets into a process of data collection. Or, put differently, how to transform many things I was in a position to witness – workshops, stories, gossip, events, and conversations – into a series of accounts that would describe the character of the ARV era in Kebbi.

Returning to Kebbi was itself an intriguing experience - Biehl describes an experience that closely matches my own:

> *"What most interests me...is the process of returning to the field. Repeatedly returning, one begins to grasp what happens in the meantime – the events and practices that enable wider social and political change, alongside those that debilitate societies and individuals, dooming them to stasis and intractability."* (Biehl, 2005:47)

I too was fascinated on my return to Kebbi to find out what had become of my old friends. Who had married, and who had divorced; who had moved

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meetings, which I often entered with apprehension, ended up yielding useful contacts.

away and who had returned, who had become sick and who had recovered, and most of all, who was largely the same as they were before, and who had changed, altered by whatever had transpired in the meantime.

Biehl, in his admirable book 'Vita' (2005), traces the path of a single life, in all its entanglements and complications. I was inspired by this approach to do something similar – a kind of hybrid between formal longitudinal research (that is, tracing an individual or set of individuals over time), and the gathering of life histories as a means of exploring a social and historical era (e.g. Yarrow, 2008). The crucial issues of the ARV era tend not be best exemplified in momentous events, but rather can be found in the ways in which relationships, strategies and bodily experiences play out over time.

Therefore, I decided that the primary means of data collection would be a mixture of ethnography and informal interviewing in which HIV positive people's past stories, present circumstances, and future hopes would be given room to breathe. A typical sequence was as follows: I would spend time with a HIV positive person that I already knew, or to whom I had been introduced. I would then outline my intentions as a research in broad terms. If they were comfortable with me, and were willing to discuss their lives, I would try to spend more time with them – visiting their homes, speaking to them at the KAPOP office, and in the case of shopkeepers and others with similar occupations, I would sometimes stop by their workplaces to chat.

The overwhelming bulk of the material I collected came from such casual, largely unplanned encounters. I learnt to be alert to unexpected digressions and unpredictable tangents – an idle conversation about football might segue into an anecdote about the speaker's relationship with his father, or a pair of women teasing me for being single might reveal something telling about their attitudes towards love and relationships.

I would often then supplement this information with a more structured ethnographic interview, typically in a person's own home. This allowed me to more fully explain the purposes of my research, how I intended to use the

data I collected, and to secure their informed consent (see the appendix for English and Hausa versions of the scripts I used). It also allowed me to ask more detailed questions about their past experiences and future hopes. Often I had heard fragments and isolated details about a person's life – the interviews allowed me to flesh these out into fuller descriptions, though as the subsequent chapters demonstrate, even these fuller narratives are marked with the unresolved and discontinuous stories that help to describe the uncertainties of living in the ARV era.

The importance of personal trajectories and histories also informed my main method of presenting data. Much of the material in this thesis is written as biographical portraits. They have been carefully edited to simultaneously excise any personally identifiable[19] information, yet retain the way in which a person tells their own story, and the telling details they mention in doing so. These sketches provide important biographical context as well as exemplifying relevant issues that are more widely observable amongst HIV positive people. Yet, I hope that they are more than simply ciphers or stand-ins for a particular type of behaviour.

Indeed, they are presented with the understanding that individual biographies are never wholly reducible to such general patterns. The narratives in this thesis are portraits that stand for themselves. As with Fraser MacDonald's approach to historical narrative essays, the stories are not subordinate to analysis, but *are* analysis – or perhaps a more powerful alternative to analysis:

> *"The essay has no deferred object; it is not 'about' something more academic, but nor does it abrogate analysis. I should stress that I do not see narrative*

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[19] I have used pseudonyms for every individual discussed in this study, with the exception of one doctor in Chapter Three who asked to be named. Additionally, in most cases I have substituted the names of specific NGOs with generic alternatives. This was a more difficult decision, but the purpose of this thesis is to understand contexts and systems, not to evaluate or blame specific organisations. I use KAPOP's real name – as it is the only organisation of its type in the region, its identity would in any case be obvious to anyone familiar with the health care sector in Kebbi.

and analysis as discrete projects, stories being subject to a detached and instrumental interpretation. Analysis does not always declare itself as such. It can find expression in allegory and be tucked away in the shadows of significant narrative detail." (MacDonald, 2013:2)

To broaden the scope and give context to these portraits, I also used various other techniques to collect data, including participatory methodologies (discussed in Chapter Six on 'intimate economies', and later in this chapter).

Analysis and priority setting

To make sense of the stories and ideas presented to me in the field, I was fortunate to have a small group of articulate and well-informed HIV positive people as trusted friends. With these people, often over a meal in the evenings, I could share my nascent ideas. Thus, I received feedback on a weekly or even daily basis from people far better informed than me. Even though the final decisions were mine, HIV positive people contributed directly and substantively to almost every stage of the data analysis.

I took only a few photographs during my time in Kebbi. This was mostly a practical consideration, as using my camera was often conspicuous and intrusive[20]. The few photos that are in this thesis are provided simply to give a minimal impression of some of the places that I discuss. Of course, HIV positive people are missing or cropped out to protect their privacy. This has the rather ironic effect of entrenching their absence, the precise opposite of what this thesis aims to achieve. The alternative of pixelating their faces as if they were bystanders in some televised crime seemed even worse.

Alternative methods and constraints

From my first visits to Nigeria, I had cultivated a close relationship with a number of doctors, including one in particular who was also a close neighbour. The conversations I had with them were equally enlightening; particularly in understanding health care systems in Kebbi and the practical

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[20] For the same reason, I used my voice recorder only sparingly.

details of HIV treatment. They also often had a strong historical sense of how things had changed over time. Again, I often shared my early ideas with them, and even gave them short papers drawn from my field notes to solicit their opinions.

On their invitation, I often spent time in hospitals, sitting in on their clinics, hanging around in waiting rooms, talking to staff, and so on. Whilst interesting encounters sometimes took place there, I nonetheless chose not to pursue the hospital as a main research site. This was partly because of the complex ethics of approaching patients in a way that avoided any risk of interrupting their treatment, or dissuading them from seeking care in the future. But it was always because most HIV positive people visited the hospital only infrequently, and for short consultations. Indeed some, in various informal arrangements, saw doctors outside the hospital, often visiting the home of a preferred doctor in the evening. Therefore, the hospital was not, perhaps surprisingly, a central part of living with HIV in Kebbi.

Research in Northern Nigeria has tended to be difficult to conduct with people of the opposite gender to the researcher. In particular, it is usually not acceptable for men to visit married Muslim women living in *purdah* (seclusion). The unique setting of KAPOP, however, meant that is was often possible to speak to Muslim women as they visited the KAPOP office. For Christian women, there was no such restriction, and I tended to speak to them in a wider variety of locations – at their homes, in cafés, and so on. In both cases, the fact that I was able to speak to women with little suspicion represented the fact they were often estranged (in various ways) from and therefore less controlled by their families and husbands.

Whilst my connections to KAPOP were key to meeting and gaining the trust of HIV positive people, I realised they provided only a limited perspective on the consequences of the epidemic in the state. After all, KAPOP comprised only a small proportion of the many tens of thousands of people with HIV in Kebbi state, and KAPOP members were by no means

representative of the wider HIV positive population in important ways (particularly in their exposure to educational sessions on living with HIV, and their tendency to be closely networked with other HIV positive people).

This restricted view of the HIV positive population was to a certain extent a consequence of the research design and my concern with the ethics of my qualitative study. Only so much can be practically and ethically done to contact a category of people that by and large conceals their membership of that category. Nonetheless, where possible I built relationships – through friends, acquaintances and chance meetings – with HIV positive people outside KAPOP. As my research project became more widely known, a number of individuals, both friends-of-friends and strangers – approached me. Several of their stories are told in this thesis, broadening out this study's focus.

One silence that became apparent in my discussions with HIV positive people was a consistent account of the politics of sustaining an adequate treatment programme. As KAPOP was preoccupied with receiving and distributing aid, rather than holding service providers to account, they were largely mute on political issues. Most ordinary HIV positive people simply had more pressing, immediate concerns than political advocacy. I wanted to explore who (if anyone) was advocating for treatment for HIV positive people (and indeed health care provision in general). This interest became Chapter Three, and required a different methodological strategy.

The two sets of actors that considered themselves advocates of HIV treatment were local doctors and a handful of international NGOs working in Kebbi. To explore how they operated, I shadowed the work of the NGO staff for several months, and conducted informal conversations and interviews with the doctors I knew. In a sense, this chapter is set apart from the others in that it foregrounds perspectives other than those of HIV positive people, and explores a different tier of activity than the others. Nonetheless, I pursued this topic as a way of referencing how political

systems and contexts shape what is required of those seeking to provide treatment.

The nature of the HIV pandemic means that there are many other topics that are worthy of consideration, but outside the scope of this thesis (discussed further in the Conclusion). I spoke to people in Birnin Kebbi and in small towns, but rarely in rural areas. I did not explore paediatric HIV, or end-of-life palliative care[21]. These and other topics are worthy of exploration – but no one account of the ARV era can claim to be complete. Instead, the examples I have chosen – the politics of advocacy in the ARV era, personal suffering, love after HIV, and the intimate economics of treatment – provide a cross section of the wide-ranging ways in which the ARV era has remade lives and institutions.

Combining ethnographic and participatory methods

I combined a number of different methods to explore particular empirical questions as they arose. Some of these methods were highly specific to particular issues or settings, and thus I describe and reflect on them within the empirical chapters themselves. Here, however, I summarise and explain the rationale for the use of these particular techniques.

Ethnographic interviews and observation were the primary methods used, and in most cases it was these methods that alerted me to the significance of particular issues discussed in this thesis. These methods were also largely adequate for exploring the local politics of health care provision (Chapter Three), though they are also complemented with secondary material from the national and local press.

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[21] The topics have been addressed in other academic literature. Research in rural areas has explored HIV treatment in terms of sexual behaviour (Apondi *et al*, 2011), mental health (Rochat *et al*, 2006), and the programmatic aspects of scaling up ARV access (Gandhi *et al*, 2009; Herbst *et al*, 2009). Children enrolled in ARV treatment programmes have been researched in, for example, Brazil (Abadía-Barrero and Castro, 2006), Uganda (Bikaako-Kajura *et al*, 2006), and Rwanda (van Griensven *et al*, 2008). Palliative care has also been widely researched: see Harding *et al* (2005) and Alexander *et al* (2012) for reviews.

Other issues required a different approach. Complex forms of suffering (primarily discussed in Chapter Four) were apparent to an extent in everyday conversation and observation, but required a different method to fully explore and describe. The premise of this analysis is that the ARV era has transformed living with HIV into a long-term issue in which the social dimensions of illness become as significant as physical symptoms. To understand how bodily illness becomes interwoven with other concerns, a biographical approach was used (see Zinn, 2005 for an overview of comparable research). This approach attempts to trace how suffering can be reduced, intensified, or transformed as social and bodily experience interact with life projects and aspirations.

I present four individuals as detailed case studies, though my interpretation of their events is influenced by my experience of a much larger number of HIV positive people in Kebbi with whom I worked. I had extended conversations with around 40 such individuals during the course of this project. However, as discussed in the preceding section, biographical narratives may illuminate broader issues, but they are not mere ciphers for them. In part, they stand alone as exemplars of the varied and idiosyncratic nature of suffering.

I take a similar approach in discussing love and marriage (Chapter Four) – that is, using a small number of case studies to discuss issues evident in a broader set of individuals. The nature of the topic, however, required various careful approaches: whilst the issues were intimate ones, in certain contexts participants were not merely willing but eager to discuss them. Especially successful was the technique of shared movie watching as a way to both start reflective conversations and provide a cast of fictional characters to act proxies for discussing real-life issues. This is discussed further on pages 149-152.

Finally, when discussing the economic aspects of living with HIV (Chapter Six), again, many issues were apparent in and explored through ethnography. However, in order to make more general statements regarding

the priorities and preferences of HIV positive people, a more systematic approach was required. To provide this broader scope whilst retaining the emphasis on the perspective of HIV positive, I used a combination of peer interviewing and participatory ranking exercises. These techniques provide significant benefits, but also invite practical and ethical complications that are discussed both in the subsequent section, and in pages 183-199 of the chapter itself.

I now turn to consider two specific areas of my research activities that were especially complex in terms of their ethics and execution: participatory research and research with suffering subjects. In the first section, I explain my experience with participatory research, and the concerns that this prompted in acknowledging the entanglements between doing participatory research and doing participatory development. In the second, I consider the additional ethical concern of working with people who suffer in diverse ways, and the general inadequacy of existing ethics protocols for devising and assigning adequate guidance for researchers.

Reflections on participation in development and participation in research

During my time with VSO, I received training in participatory techniques. Indeed, Robert Chambers himself led (or at least 'handed over' the leading of) workshops with my cohort of volunteers in Birmingham prior to our departure. I was, and remain, greatly inspired by Chambers' (1994; 1997) advocacy of participatory methods: the potential to reverse the usual power dynamics of development and research is an irresistible goal, even if it is so often proves illusory. My experience with these techniques was uneven, and involved both political as well as practical problems. This is little point glossing over these difficulties – instead I reflect on them in the following sections.

Out-of-focus focus groups

The first experiments with participatory methods I made were in exploring suffering (as discussed in Chapter Four). Based on the literature and my

prior experience, I had in mind various broad ideas regarding suffering: 1) it is social, that is relational, and involves decisions about navigating and creating social worlds; 2) it has differentiated outcomes which can't be assumed or presumed directly from biophysical indicators; and 3) that I, as a researcher, therefore am implicated in social suffering, capable of interacting with it, alleviating it, or exacerbating it. Finally, 4) Because of the difficulty in articulating suffering, particular research strategies are required. That is to say, it is necessary to devise methodologies which help people express things that they have never really spoken about or articulated before.

Given this interest in common aspects of the experience of suffering, and that many KAPOP members knew each other, and were comfortable discussing sensitive topics (at least to a point) with each other, focus grouping was an attractive method to articulate hard-to-discuss topics. Indeed, the technique is a mainstay in qualitative health research of this kind, and has been widely used in studies of HIV adherence in North America (Proctor, Tesfa, and Tompkins, 1999), South America (Nemes *et al*, 2009), Asia (Hansana *et al*, 2013) as well as sub-Saharan Africa (Hardon *et al*, 2007).

In 2010, I planned and set up some of these focus groups as a form of pilot study. I used small groups of 3-6 people, and used a mixture of open-ended questions, followed by some simple ranking exercises. Over a five-week period, I conducted four focus groups, two with female participants, one with male participants, and one mixed. Using KAPOP members, I was able to mitigate some (though by no means all) of the issues relating to confidentiality and reluctance to discuss sensitive issues (it was also clear from prior experience that single gender groups led to a more open discussion – the mixed group was improvised at short notice to take advantage of the presence of several rarely-seen members and did not work as well).

These focus groups were not a complete failure. Indeed, they emphasised a number of interesting topics. For instance, they underscored that for many suffering was about anxieties over the future, and emphasised that

significance of remarriage (as discussed in Chapter Four). However, the conversation often had a formulaic, rote quality to them, and many of the discussions got stuck at a superficial level. For instance, during each meeting, a participant mentioned the topic of being estranged from family. But rather than the comparative, insightful discussion I had hoped for, the conversation stayed at the level of generalities. Further, members often made comments along the lines of "HIV positive people can be abandoned sometimes, so it is important that we are able to come together". This sounded very close to the standard responses that I had seen offered when other outsiders, such as NGOs or government officials, visited.

The politics of participation

Whilst this limited form of participation proved at best partially effective, I had more success exploring the economic issues of treatment that I explore in Chapter Six. There, I used both a form of participatory interviewing, and particular ranking exercises. In the case of the ranking exercises, I deliberately used a technique that the participants were familiar with through its use by other development organisations. This familiarity made conducting the exercises more straightforward (as I had hoped). However, given the imperfect way in which NGOs tended to use the techniques, it also raised a series of uncomfortable questions regarding the difficulty in using participatory techniques in a way that is genuinely empowering. Similarly, that participants in the previous exercise engaged with me as if I were an authority figure to be appeased was troubling.

Participation is a concept that is important to both some of the development projects that attempt to improve the lives of people in this study[22], and the methods that I have used to research them. Participatory development and participatory research share a great deal in common, including intellectual antecedents and an agenda to make a sometimes alienating process more open and empowering towards its subjects. It could be claimed that

[22] Indeed, the whole concept of a support group relies a certain form of participatory logic, emphasising self-help and empowerment.

participation implies making development interventions more like critical social science research (by prioritising the collection and use of local knowledge), and research more like development (by making the inclusion and empowerment of research subjects an objective, sometimes with even more explicit aims of politicisation or activism).

The trajectories of the two sets of interventions have (rather like the NGOs discussed in Chapter Three) prompted initial optimism by both researchers and practitioners, followed by a fuller realisation of the difficulties and complications inherent in such projects. Given the similarities of these two projects, in this section I juxtapose a discussion of participation in development with a discussion of my own attempts at participatory research. Aside from the thematic intertwining of these topics, presenting this material side-by-side is intended to emphasise that my research is by no means immune from the hypocrisies and disappointments of participation.

Participation for development

Participation has evolved from a fringe subject to a central tenet in development theory and practice, with organizations like the World Bank – generally immune to non-economic methodologies even when incorporating new ideas (see Bebbington *et al*, 2004) – showcasing its participatory tendencies at a range of scales (see Bebbington *et al*, 2007). Despite the ubiquitous and apparently straightforward deployment of the term in development discourse, participation has driven ambivalent and ambiguous changes. These changes can be elucidated by way of an intellectual history of participation in development. Also discussed below is how 'participation' is closely related to particular conceptions of 'the local', which themselves have complex political consequences.

As I attempt to explain here, participation is largely a response to both practical problems in development, and critiques offered by postdevelopment authors. Development scholars and practitioners must

continue to balance the successes of participatory methods in revitalising aspect of development with their many limitations and disappointments.

From postdevelopment to participation

Critical opposition to development has a long history, but is frequently phrased within the Marxist language of dependency and underdevelopment (for influential versions of these critiques see Rodney, 1992; Shenton and Freund, 1978; Palama, 1978 and Cooper, 1981), leaving a focus on technical solutions, economics and growth unchallenged. More recent authors tend to look less to Marx but rather to Foucault for their analysis of development – and it is within these critiques that participation has gained traction.

For postdevelopment thinkers, development, "stands like a ruin in the intellectual landscape", having "grown obsolete" (Sachs, 1992:1). For such scholars, the failure of development is axiomatic – an understandable but problematic assumption, given that they tend to downplay development's achievements in healthcare and education (Corbridge, 1998:145)[23]. Reform tends not to be the aim, rather, they aim to show that the concept of development itself is no longer a useful way of organising social action against poverty. Following Edward Said, they argue that development practice relies upon a well-meant but disempowering conception of the poor that, ironically, becomes part of the problem (Ferguson, 1994; Escobar, 1994).

However, the complete rejection of development as a route for alleviating human suffering was more sceptically viewed by scholars involved in conversations with practitioners dedicated to improving development practices. The roles that participation has played within development can be divided into four time periods. Firstly, there is the era of participation as radical dissent from the modernization consensus of the 1970s. This was shown by a group of mainly rural sociologists who proposed that development should have a greater local and endogenous quality. The

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[23] Many elements of these debates are replayed in more recent disputes between broad defenders of aid such as Jeffrey Sachs (2005), and more critical voices like William Easterly (2006) and Dambiysa Moyo (2009).

Brazilian educational philosopher Paulo Freire influentially argued that liberation "must be forged with, not for, the oppressed" (2005 [1970]:48). And so, argued the radical sociologists, must social change. Secondly, from the 1980s onwards, led by Robert Chambers, more explicit and systematic attempts to integrate local people in development activities were made. These arguments and activities proposed that local participation was the missing ingredient, the absence of which severely compromised both the potency and the legitimacy of development interventions. Next, there is the modern era – particularly from the mid 1990s - in which participation in development is ubiquitous and mainstream (McGee, 2002). Finally, there is a fourth period, in which academic scepticism of participation became more widespread.

Intellectual origins

Though there are several influences explaining the emergence of participatory approaches to development, both neoliberalism and localism were critical to their success. Perhaps ironically, alongside radical left-wing political ideology, the neoliberal ideas and practices also helped catalyse the growth of participation. A "profoundly cynical and pessimistic private interest view of the state" (Mohan and Stokke, 2000:250) provided the intellectual context, whereas the dramatic reduction in government service provision under structural adjustment programmes opened up new spaces for various kinds of new actors to fill in new ways.

The concept of localism, which can be roughly defined as increased attention paid to local communities as an important level of analysis and site for economic, social and political action, is also implicated in the shift towards participation. As Mosse points out, the incorporation of local knowledge into interventions is seen by many as, "the dominant understanding of participation" (2001:16). If local people cannot offer anything new and significant to assist in their own development, there is no reason for them to participate.

Yet, just as previous approaches to development have relied on a helpless and hapless vision of the poor, participatory methods necessitate a naively misconceived view of 'the local'. Deconstructing these conceptions and exposing what Mohan and Stokke call 'the politics of the local': the hegemonic production and representation of 'the local' and the use of 'the local' in counter-hegemonic collective mobilisation" (2000: 249).

The first aspect of the 'politics of the local' is the view that communities are neatly segmented into discrete spatial units. The reality, of course, is far messier. This may come in the primacy of cultural links over geographical ones (Pratten and Baldo, 1996), or 'communities' may be non-spatial and international in profound ways, such as disruptions of Cartesian-based ideas of community by networks of migration and remittance. Discussion of this development/community/migration nexus has been a significant topic for recent research (for example Ammassari & Black, 2001; Black & King, 2004; De Haas, 2010; Nyberg-Sorensen *et al*, 2002), a concern anticipated in earlier studies (e.g. Lipton, 1982). These external links are not only through family and finance – religious institutions, for instance Pentecostal churches (Hackett, 1998; Van Dijk, 2001), may also provide connections to international networks. Success is therefore unlikely if a community is treated as if it were a neatly bounded island, when it is, in fact, nothing of the sort. The pervasive nature of various forms of international links suggest that more people inhabit the 'remotely global' villages described by Charles Piot (1999) than Manuel Castells' (1998) 'fourth world' of black hole like disconnection.

A second aspect of 'the politics of the local' is the tendency to depict communities as unified and harmonious (Cleaver, 2002: 231), or at least capable of presenting a coherent, representative view on everything from development aims to preferred practices. A variety of empirical and theoretical studies have impeached this notion. Mosse argues that "'local knowledge' reflects local power" and is "highly differentiated in terms of who produces it" (2001: 21). Kumar and Corbridge (2002:79) note that within a community, the relatively privileged are often able to subvert participatory

processes, capturing aid aimed at the very poorest – even by strategically misrepresenting their economic status. This particular practice, as we shall see, is highly relevant for this study.

The situation in Kumar and Corbridge's study is further complicated by differing ethnic groups within the community, which also influence the course of the project. Unlike the project's idealistic (British) administrators, they do not necessarily see this as evidence of failure, pragmatically accepting that "development will occur as it always does, slowly and unevenly" (*ibid*:98). On a similar note, Hoang *et al* propose optimising participation by taking note of "power relations that are deeply embedded in local social networks" (2006: 513), as these stratified stocks of social capital are just as likely to distort interventions as more concrete material inequalities.

The way in which participatory methods tackle these power disparity issues has also been an area of criticism. Uma Kothari (2001: 139-145) has reservations about Chambers' simplistic, binary conception of power; something an individual either has or does not have.[24] It is inevitable, perhaps, that she should turn to Foucault to complicate this picture (as John Hailey [2001: 97-100] does in his piece in the same volume). While it is valuable in this context to conceptualise power as fluid, semiotic and discursive, equally interesting and original is Kothari's appeal to Erving Goffman. The popular concept in participatory methodology of the benefits of 'getting things out in the open'[25] (for the purposes of challenging cultural

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[24] In his other work, developing the influential sustainable livelihoods framework, Chambers see human welfare as a complex, shifting blend of capabilities, assets and activities (Chambers and Conway, 1992: 6). It seems odd, then, that he should persist in using an apparently dichotomous conception of power (he was still using the terms 'uppers' and 'lower' liberally at training sessions I attended in 2006 and 2007).

[25] For ActionAid's Star Project (2007) for instance, it is the *sine qua non:* "If there is no open discussion of power relationships within groups, analysis often remains at a superficial level".

restraints)[26] is inverted by Goffman's interactionism which suggests that the more public the setting, the more significant "impression management" will become (Goffman, 1958). We cannot take at face value any claims made, agreements reached or consensuses built at participatory workshops, because in public "events, actions and performances, and selves do not always speak for themselves but rather depend on framing for their meaning" (Branaman, 1997: xlvii).

Ethnographic accounts of such development actors, following James Ferguson's work, are thus essential to work out what is really going on within development projects. Harri Englund's (2006) monograph *Prisoners of Freedom* is a valuable example, especially the account he provides of a community outreach programme designed to deliver a civic education syllabus, apropos to the new democracy of Malawi. It is worth discussing at some length, not least because so much of his description resonates with my own experiences of running and observing comparable events. The project Englund studied was large-scale – educators were hired nationwide and the project was run with a budget larger than some government departments (*ibid.*: 76). But Englund is mostly concerned with subterranean messages, especially the (mis)translation of human rights and a perversely stratifying form of participation.

Human rights are a key part of the syllabus taught by the civic educators. Englund suggests that this could work positively for the purpose of participation, but in reality such messages are gutted of social and economic concerns, and reduced to narrow political topics such as representation and free speech. This is partly as a result of sloppy translation from English to Chichewa – "poor translations for poor people" (*ibid:* 54), Englund bitterly quips – but also reflects the interests of the middle-class NGO workers that advocate for such rights. For Englund, the version of human rights that reaches poor people – filtered through both local elite and global neoliberal

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[26] On culture as a restraining, inertial force upon development see, for instance, De Haan (2000: 7) and De Haan & Zoomers (2003: 357).

interests – is neutered and powerless. Little wonder, then, that the rural poor should struggle to see the relevance of the concept.

In descriptions that closely matched my own professional experiences in Nigeria, programme sessions were supposedly participatory, but the form of facilitation Englund witnessed was not. It featured the trappings and buzzwords of Chambers' Participatory Rural Appraisal, but with little attempt to include views not in the script: "officers' preoccupation with 'right answers' gave them little chance to actually listen to what transpired during the small-group discussions." (*ibid.*:107).

Furthermore, oppressive power relations were not only left unchallenged but were actively reinforced. White reaches a similar conclusion assessing Bangladeshi NGOs: "while participation has the potential to challenge patterns of dominance, it may also be the means through which existing power relations are entrenched and reproduced" (1996: 6). In a variety of subtle and not-so-subtle displays, such as dress, conspicuous mobile phone usage (Englund, 2006: 104), the use of "improbable titles such as 'Hon.' and 'Doctor' before their names" (*ibid.*: 86), and publicly correcting colleagues' mistakes (*ibid.*: 87), senior project staff differentiated themselves from the village educators. Englund sees this as a pacification of the rank-and-file members; an important political function, given that the characteristics of these educators – young, educated, politically engaged – which makes them potentially powerful challengers to the status quo (ibid. 79-81). The educators in turn differentiated themselves from locals. Even when working in regions in which they grew up, teaching people no worse off materially than themselves, the educators would emphasise their difference through appearance, cleanliness, education and command of English (*ibid.*: 87-93). All of these observations, again, found ready parallels in my Nigerian experience. The conclusion is hardly an encouraging one: a project pledges to turn top-down development on its head. The goal, it promises, is not set by foreigners, but agreed with and by the people. Instead, the poor are subjected to ever more pervasive and hegemonic disciplinary techniques.

Clearly, it important to carry the analytical tools and sceptical spirit of postdevelopment into analyses of both 'old development' practices and the proposed solutions. Even if 'de-naturalised' (Nustad, 2001) the casual oppression of an earlier development era can easily be reproduced in the 'new tyranny' of participation, to use Cooke and Kothari's (2001) formulation. Development practitioners are at least equipped with the theoretical tools necessary for critical self-reflection. Compared with their predecessors in the modernisation era, they will have fewer excuses if they fail to author a more empowering, less dominating role for themselves. But it is important to clarify that the influence of ideas about participation and knowledge in development are evident beyond debates about development practice, and into broader considerations of the relevance for research on themes that stretch beyond the standard 'global south' confines of international development concerns.

Participation for research

I now turn to participatory action research – which I will abbreviate as 'PAR' for brevity's sake, even though, as discussed below, the levels of 'P', 'A' and 'R' are highly variable. This section is not an attempt at assessing the scope and efficacy of PAR, (see Pain, 2004 for such a review). Rather, it is an attempt to justify a research design that combines PAR and non-PAR methods: my attempt at a context-appropriate research strategy that tries to recover what remains so exciting about PAR, whilst being careful and honest about both the limitations of the technique, and my use of it.

PAR occupies a highly ambiguous conceptual position. It is at once a method, a methodology, perhaps to a limited degree an epistemology (in that it involves assumptions about the collaborative nature of knowledge), and often a political ideology or agenda of some sort. These are not easily prised apart from one another. It is difficult to judge participatory methods - the bread-and-butter tools and exercises which constitute the technique - without assessing the coherence and value of the political goals that motivate their deployment. Nor is it possible to fully evaluate the ideological and

epistemological underpinnings of PAR without considering the extent to
which PAR methods produce material of worth.

These rhizomatic, complex exchanges between practice and theory are
central to what PAR is, and what people are trying to use it for. In other
words, participatory practitioners are not just confusing matters by using the
same label to describe different things (though they certainly do this at
times), but they are also making a sincere and at times powerful attempt to
disrupt established ways of doing theory and research.   To understand the
diversity of PAR as practiced, along with its ambiguous conceptual position,
each part of the PAR process will be considered in turn.

PAR as method

PAR is perhaps most readily identifiable by a set of techniques. These
generally take the form of group discussions structured by certain types of
'tools', often involving ranking exercises, mapping, and idea generation.
Photography and video have also been used, especially more recently (e.g.
Kindon, 2003; Vincett *et al*, 2012).

Sets of tools are themselves interesting, even if not always used as part of a
participatory programme. These methods are particular – the use of, say,
video, or ranking techniques – are not neutral but produce particular kinds
of outcome. As Mike Kesby argues:

> *"there is little that can really be said about a particular technique
> independent of the theoretical framework within which it becomes a tool"*
> (2000a, 423)

But the reverse is also true – that the theoretical framework of PAR is deeply
dependent of the particularities of the techniques used. Asking a group of
people to rank the seriousness of diseases on a table (as Kesby, 2000a does),
or to film a participatory video (Kindon, 2003) will produce results that are
shaped by the concrete experiences of the technique; the type of research
encounter in which it takes place; and other dimensions that might be

otherwise viewed as external to the aims of participation, such as fads in popular culture or specific group dynamics and recent life events[27].

Though there are an increasing number of books, articles and even journals dedicated to PAR-related methodological interests, there have been calls for greater emphasis on the 'soft skills' of PAR, the emotional sensitivity, and the charisma required to actually carry out good quality participatory work[28]. Natascha Klocker (2008, 2011) demonstrates this reflexive approach in her investigation into child domestic work in Tanzania and provides an extended, instructive and honest set of reflections on what actually happens in PAR. Issues discussed include situations in which researchers must sometimes take more control over the process than they would like, the emotional burden research can place on researchers, and how not everyone is well-suited for the kinds of open exercises PAR uses.

Such 'home truths' stand in welcome contrast to many accounts which Klocker rightly describes as glossing over some of the difficulties involved in PAR, presenting a slick picture that is not only misleading but discouraging to young researchers (for a similar reflections, see Jupp, 2007). At any rate, they certainly gave me reassurance when things went awry during my research.

PAR as methodology

As well as a toolkit of techniques, PAR poses a radical set of questions about research practice. Obviously, it critiques the notion of the identity of researchers, suggesting that meaningful and useful knowledge can be produced without a skilled, specialized professional as its source. It also provokes a re-sequencing of the usual ordering of research, allowing the

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[27] Elizabeth Olson and Giselle Vincett (2010) discuss this in an unpublished paper reflecting on participatory audio-voice projects with young people in the UK.
[28] These journals include 'Educational Action Research', the 'International Journal of Action Research', and 'Action Research'. Some examples of reflections on participatory techniques include Lemelin *et al* (2013), Quinlan (2010), and Collie *et al* (2010), see also Dick (2011) for an overview of recent trends.

researched community to explore issues and set an agenda rather than proceeding from a pre-determined research question.

Taking these challenges in turn, the notion that 'laypeople' can be competent researchers is clearly at the core of PAR. But as a growing body of literature demonstrates, this assumes a very particular relationship with the research community. Reiterating the argument in the above section that the worth of 'local communities' has become "the dominant understanding of participation" (Mosse, 2001:16), but one that risks romanticising or otherwise misapprehending those communities. Thus there is a risk that by trying to open out the research process in some ways, it is closed down in others, through a preconceived idea of who the research subjects are and how they interact with one another.

As discussed below, a 'pure' participatory project is inordinately challenging within the confines of a doctoral thesis that is reliant upon specific deadlines, conscripted data-gathering fieldwork, and long periods of 'writing up'. Similarly, the 'action' component of PAR – providing benefits for research participants that goes well beyond the usual *quid pro quos*, is difficult to achieve in the scheduling and resource constraints of a doctoral programme. Finally, handing over control of research projects to others may be a stimulating and creative process, but it is also a risky one, requiring a tolerance for blind alleys and potential failure. These problems that are frequently noted in participatory work can be even more challenging for those students without established reputations or extensive experience to fall back on.

PAR, knowledge, and professionalization

PAR can create new knowledges, as well as access pre-existing or latent ones. But as discussed above, it does so in particular ways, with epistemological implications. For instance, various types of mapping and diagrammatic techniques used emphasise visual and spatial understandings, avoiding a tendency to privilege the written word (Kindon, 2000; Pain, 2004). Similarly, as with conversational analysis and performative approaches, welcome

attention is directed towards the interactional way in which people make sense of the world and their lives. However, PAR is also often distinguishable from ethnomethodological approaches in important ways. In the content analysis of scholars like Goffman, for instance, attempts to analyze behavior require contexts not created by research techniques like interviews or focus groups. Though some participatory research acknowledges the research context itself as distinctive, there is a tendency – perhaps particularly amongst PAR practices in development contexts – to present findings as unproblematic reflections of 'real life' (see, for instance, Chambers early justifications for the importance of PAR).

Given its early emphasis on accurately representing previously underappreciated 'local' knowledge, it is not surprising that, PAR takes academic research and academic publishing as potentially problematic (Jupp, 2007). Much social scientific thought since the cultural turn has reflected concern about the kinds of truth social enquiry produces. PAR presents one pragmatic attempt to address some of these complaints. In particular, it provides a framework for rectifying traditional academic research's sins, variously held to be masculine, white, and neglectful of children's perspectives (Raghuram & Madge, 2006; Kindon, Pain and Kesby, 2008).

PAR practitioners in and outside the academy typically frame their research as part of a struggle for social justice. This of course begs the question, to borrow Robert Chambers' syntax, whose social justice? Given a conservative Islamic worldview, many in Kebbi and elsewhere in Northern Nigeria would clearly find a project that aims to give equal voice to men and women problematic. Disrupting such gendered hierarchies might be attentive to subaltern views, but also dismissive of sincerely held local religious ones. The process of 'handing over the stick' (Robert Chambers' metaphor for handing over power) might be disruptive and potentially ethnocentric, embodying as they do many of the democratic ideals of Western liberalism.

Reflecting on PAR as practiced in development, as in the previous section, demonstrates ample scope for participatory methods to end up overbearing

and disempowering. Such limitations have been discussed widely, but advocates of participatory methods still point to the potential for PAR to disrupt power inequalities in the production of knowledge. Kindon notes that "most conventional research practice continues to rely on external experts who define the research problem and process, they observe and extract information from (passive) subjects over a relatively short time period, often analysing the information generated alone and objectifying their informants in the process" (2003: 149). She also expresses disdain for "voyeuristic, distanced and disembodied claims to knowledge" (2003: 142). What is more difficult to engage with, perhaps, is the relationship between participatory approaches and methodologies such as ethnography, which is certainly a 'traditional' approach to the generation of knowledge. A long tradition of anthropologists who spend years not only studying, but living with, working with, sleeping with, perhaps marrying their 'subjects', could hardly be said to be 'disembodied', at least.

More likely, critiques of traditional approaches are more in reference to those methodologies that became favoured after the positivist turn in social sciences, and it is common for more overt participatory approaches to take place alongside ethnography, observation, and other 'traditional' methodologies that come from humanistic and ethnographic traditions.

PAR in Nigerian support groups

As a population that is deprived, hidden, discriminated against and silenced in public debate, the political motivation for using PAR with HIV positive people is obvious. Working in an comparable Brazilian context, Biehl argues that the worst-off ill people cast out from both familiar and state support services are in a 'zone of abandonment'. As the chapter on suffering explores, they may not be literally voiceless, but have drifted into "a human condition in which voice can no longer become action" (Biehl, 2005:11).

In such circumstances a link has been severed: expressions of subjectivity no longer have objective consequences. PAR then has two overlapping goals.

The first is to in some way enhance how HIV positive people communicate. Not so much to 'give them a voice', but to the make the voices they already have more potent and audible to new audiences.

The second objective is more to do with the passive collection of data. It must be recognised that support groups exist, in part, to carry out precisely this process of empowerment that PAR aims to bring about. Because of many of the epistemological and practical issues mentioned above, my own research focused on what people do together in these groups – how they collaborate, share and contest medical knowledge, and make sense of their changed lives. In a sense, by asking people to take part in a participatory exercise – for instance, ranking different types of illness – I facilitated a condensed, accelerated version of the work they already do, lending an ethnographic eye to the process of participatory exercises. This thesis thus includes classic participatory exercises of encouraging people to create their own account of something. But as well as facilitating the creation of new knowledge, I paid attention to how knowledge was being created, rather than treating the outcome of such encounters as 'data' that might be analyzed for the purpose of understanding those living with HIV.

One of PAR's great strengths is that it directs an unrelenting gaze towards the ethics and power relations of research. Once PAR has been used for the first time, one can't help but see other research methods in a different light. The challenge is to put this mindset to productive use, for instance by exploring how participation and non-participatory research techniques can be syncretised productively. However, issues related to power are not the only ones of consequence in research ethics. In the remainder of this chapter, I explain how I approached the ethics of researching with people who are suffering.

The ethics of researching suffering

In Chapter Four, I review a range of literature about social suffering. My concern with suffering, however, emerged not from a theoretical interest, but from the experience of working with people who were often times suffering,

though in complex and changing ways. These present particular problems that are not always evident in all participatory research, and also suggest that some of the best practices generally associated with PAR – shared knowledge, collectively generated conclusions – are not always a good fit with topics that address intimate experiences of suffering. In this section, I reflect on what the risks and potential benefits of research encounters with suffering people might be. This overlaps with – but is not identical to – similar debates regarding researching vulnerable people and sensitive topics.

The material presented throughout this thesis describes, quotes, and evokes the most intimate and sensitive conversations I had during my visits to Nigeria – or for that matter, at any time during my life. Like other comparable projects, this research involved a complex set of ethical issues. These issues apply throughout this thesis, but they are particularly acute in this chapter, so I take the opportunity to explore them at length here.

The arguments below explain and justify the choices I made, in so far I am satisfied that I made a reasonable set of judgements regarding some highly complex issues. I also argue, however, that the usual means of verifying that social science research is conducted ethically is entirely inadequate to projects such as this.

Research in developing countries

As Brydon argues, the distribution of power sets the context for the consideration of research ethics:

> *"any research context is riddled and cross-cut by relationships of power, from those between the sponsors of the research and the researchers, and between the researcher and the researcher, to power relationships within the culture of the research setting, relationships between classes and clans, landholders and landless, educated and illiterate, elders and juniors, women and men, rich and poor"* (2006:27)

All these axes of power are relevant for this project. A particularly intensifying factor is the role of the Westerner conducting research in a poor region. The power disparity that this implies cannot be universally assumed – indeed, below I suggest that many of the people I encountered had access to various sources of power. Nonetheless, it is a broad truism that a researcher based at a Western institution carries considerable influence and privilege into the field, a power modulated and intensified through race, language, gender, and money.

This truism was certainly evident in this project, as I felt my privilege manifest in all sorts of situations, both serious and trivial. On one occasion, I visited a rural health clinic about two hours drive from Birnin Kebbi. It was in the home village of a doctor friend who had been nagging me to visit for many months. I finally made the time to visit during a slow week. I had planned to do little more than drop-in, greet various acquaintances of my doctor friend, and ask a few general questions of staff at the clinic.

When I arrived, advanced word of my visit had caused a stir – all the staff at the clinic, and various local officials, some of whom had travelled some distance, were assembled, waiting for me. When I spoke to staff at the clinic, I asked a few questions that I hoped might make me sound polite and interested, and was ushered to a nearby home to see an old man, clearly very sick, who was said to have malaria. I was embarrassed that what I imagined as a courtesy visit had been misconstrued, embarrassed that busy people had disrupted their day for me, and most of all, embarrassed that I might be contributing to, even if only in a minor way, to the suffering of people.

This was an example of a common situation in which "investigators and sponsors from [high income countries] often enjoy relatively high levels of access to senior officials in healthcare and politics in [low and middle income countries] hosting the research" (Lavery, 2004: 327). Thus I was aware that my position allowed me relatively unfettered access to suffering people. The challenge, then, became to develop a practice that avoided continuing or

adding to this suffering, avoiding any further dehumanisation, particularly when individuals had only a limited ability to protest.

To try to mitigate the worst of these risks, I developed a 'two-speed' way of working. This meant working in a more or less conventional manner with HIV positive people that I knew well, but being extremely cautious in making new contacts. Both groups involved different issues.

Those that I knew well: these comprised predominantly of people that I knew from my volunteering work in 2006-7, but also included other HIV positive people I had come across in various ways. In terms of their HIV status being known to others, some were tacitly 'out' to various family members and friends, whereas others had disclosed their status only to one or two others, often other support group members. A handful – mostly just the senior management of the support group – were completely 'out' publically, and spoke as such at various events.

In each case, the individuals were by necessity skilled at maintaining whatever status they had chosen. They would advise me, often indirectly, when would be a discreet time to visit them, often suggesting a pretext for which I might plausible be visiting them - 'you can tell them I teaching you Hausa!' suggested one.

For such individuals, the main ethical concern came in protecting their privacy, and in negotiating my role as a broker of information and advice. I address the latter point in a later section, but in terms of preserving confidentiality, this largely meant avoiding becoming an inadvertent gossip. It was of great value to ask one HIV positive person to reflect on something another had said or done – but to do so I took care to make such information unidentifiable. A common technique was to retell a local story as 'something I heard in Kano', or some other Northern Nigerian city.

Those that I did not know: A more difficult problem concerned the willingness of my various friends to put people they knew to be HIV positive in contact

with me. Such introductions were welcome, and often resulted in fruitful connections. However, unlike with established contacts, it was often difficult to learn in advance about their family situation, position regarding the 'HIV closet', and general disposition. Without such information, the risks involved in making contact for the first time were severe.

The dangers of inadvertently 'outing' someone through meeting in an inappropriate venue, or of causing upset by raising an unexpectedly sensitive topic were acute. To mitigate these risks, it was necessary to act with great caution – in particular adopting two 'golden rules' and one 'silver' rule. The golden, unbreakable rules were:

1. *Always leave a gap between explaining my research aims and goals, and setting up a later interview or meeting.*
2. *Always allow the interviewee to set the logistics of the interview.*

I adopted *1)* after realising that when asked face-to-face in a first meeting, people were all but obliged through some combination of politeness and my prestige to accept almost any proposal I made. Even taking care to explain my research purpose and methods in an accessible way (which took many iterations to do adequately), such a context precluded full consent. Instead, I would explain what I was doing, and only much later (at least a week, but often much longer) suggest a further meeting. Even then, further explanation and discussion was required to make sure my project was fully understood, but it at least gave potential interviewees time to consider and perhaps consult with others to ask about my activities. More straightforwardly, *2)* assumed that interviewees themselves are always likely to be the best judge of a discreet (but not suspiciously clandestine) time and place to meet.

A third 'silver rule' was 'avoid speaking to people about their HIV status in the presence of others, including those making the introduction'. This may seem an obvious provision, but often introductions took place organically. For example, on one occasion early on in my research, a lady I knew well

invited me to her one-bedroomed flat for a meal that she and her friend from church would prepare. She discussed her HIV history openly, making it clear that her friend was a trusted confidante. But then my host pivoted the conversation to her friend 'my sister actually has the same issue as me…', encouraging her to discuss her experiences. This was, to say the least, uncomfortable. My host's friend appeared to be willing, albeit shyly, to talk about an experience she had switching her medication. But I had no way of knowing whether the friend was consenting voluntarily, or speaking from a position of obligation, solidarity, or perhaps even subordination.

This example is particularly relevant, as I met a great many of my research contacts in a similar manner. Given how problematic this situation was, I resolved to close down, as tactfully as I could, any such conversations with a 'third party' when they arose, saying that perhaps we could talk about it another time. In truth, however, it is only a 'silver rule', as there were several unique situations – for instance, one memorable occasion when a male friend of a friend related in a very amusing fashion his own struggles to conceal his (opportunistic infection related) skin complaint, including a secret experiment with make-up. Such situations were treated as *sui generis*, and it seemed reasonable to ask for retrospective permission to take notes based on them.

The rules I developed relate to my understanding of the different categories of suffering expressed in the literature review above. That is, articulating suffering can be powerful and emancipatory – a process I hoped when possible to be a part of. But also that suffering can strip people of their sense of autonomy, agency, and ultimately humanity – clearly a process that a researcher must avoid deepening.

Research with vulnerable or suffering subjects

Rather than discussing suffering explicitly, discussions on research ethics tend to use the term 'vulnerability' to denote a group of research subjects to be treated with special care. This understandable notion is nevertheless a rather blunt instrument, as the complexity of suffering requires some nuance

in determining what is appropriate. Someone can be vulnerable but still be entirely capable of making good decisions about their participation, but perhaps someone who is not 'vulnerable' but is suffering would not. Or in other words, we assume someone who is suffering is vulnerable, but that actually tells us very little about the impact of research conversations and interactions with them.

An underlying assumption of conventional discussions on research ethics is that interaction has the potential, first and foremost, to cause harm. Formal research procedures usually involve a special category for 'vulnerable people' or similar, research with whom requires special precautions. As Liamputtong (2006:2-5) suggests, people may be deemed vulnerable for all sorts of reasons – and many of the categories appear to apply to this study: marginalised, with precarious livelihoods, 'hidden', subject to potential sanction and so on.

In some sense, then, all the participants in this study are 'vulnerable'. However, that vulnerability is by no means equally distributed. Several KAPOP members were relatively well-off, and including several who, as previously discussed, made no secret of their HIV status. They were not obviously more vulnerable than anyone else in Birnin Kebbi.

Others, however, were more at risk. At no time did I speak to children about the issues of this research. Children certainly could be ethically involved in research such as this; with Mike Kesby's work in Zimbabwe (Kesby, Gwanzura-ottemöller and Chizororo, 2006; Kesby 2007) as one such example. I was also privileged to witness in progress a brilliantly imaginative participatory research project involving young Qur'anic students in Kano (Hoechner, 2011, 2013). However, for this thesis, I chose to focus on issues of suffering, romantic relationships, livelihoods and institutions from the perspective of adults.

I also avoided speaking to those who were unwell at the time. 'Wellness' is relative in the context of HIV positive people, but for this purpose it means

anyone who had or appeared have any condition that might impair their judgement and ability to consent to the research, or that might make a discussion uncomfortable in some way. Before and during this project, I spoke to several very sick people, often when I was invited to accompany someone to visit a sick relative or friend in hospital. None of these events are discussed here, even via pseudonym.

More broadly, in a context such as this, scholars could benefit from a more careful consideration of what it is to suffer. The differing ways in which people suffer (through social stigma, or physical pain and so on) could dictate how vulnerable they are to negative impacts of research. The research process itself has the potential to be harmful, as does the process of writing.

However, there is an intriguing alternative possibility that the research encounter might very well prove to be a positive one. The people I talked with often said that they enjoyed the chance to talk at length about their situation, that it was helpful to be listened to. Far from being risky, potentially unpleasant encounters, the vast majority of conversations I had were friendly, reflective, and often playful or even flirtatious. This can be understood in part as a logical extension of the notion described above that suffering is most potent when it cannot be articulated, and becomes more manageable once spoken.

There is significant potential, then, for the research process itself to act as kind of therapy for the participant, or at least as a form of positive affirmation or reassurance.   After all, as Birch and Miller point out "the endeavour to create a successful interview can be likened to the processes employed by other professionals – counsellors and therapists – involved in therapeutic work" (2002:190). Ealasaid Munro (unpublished paper, 2011) has pointed to small range of literature that acknowledges this possibility, particularly the work of Liz Bondi (1999, 2003).

In summary, suffering does not straightforwardly equal vulnerability; as people suffer in different ways; that vulnerability cannot be reliably affixed to a group of people. Indeed, if this is not appreciated, researchers may, in an effort to avoid exaggerated or misunderstood risks, miss opportunities for their research to have immediate positive effects.

Ensuring ethics

The above sections outline some ethical risks and practical strategies for mitigating them. This reflects a decision to privilege 'ethics on the ground' over 'official ethics', to use Heimer's (2012) distinction.

'Official ethics' refers to the formal procedures involved in certifying research, typically following the biomedical model of avoiding harm. This forces responses in a more or less mechanical fashion to issues such as informed consent, confidentiality, and the various perils of researching sensitive topics and vulnerable subjects. That was the focus of my methodology training, and it was certainly the point of the ethics review conducted as part of this thesis.

Various scholars have drawn attention to the inadequacies of such an approach. One issue is the attempt to develop and apply a universal system of ethics across different contexts (Molyneux and Geissler, 2008). Another is that such 'licencing models' tend towards superficiality, privileging "form over content" in a way that often amounts to little more than "adjusting the wording of consent forms" (Heimer, 2012:3). Most crucially, through a tick-box approach, the process of 'official ethics' "displaces personal morality" (*ibid.*:8), creating in many cases unnecessarily narrow limits on the responsibility of the researcher.

So, whilst ethics reviews can be useful, they represent at best a limited engagement with one part of a much broader issue. However, it is one thing to demonstrate the limitations of official ethics, yet quite another to formulate an alternative practical strategy for protecting participants. This

suggests an emphasis is more on "doing ethics" than rather than "discussing ethics" to use Molyneux and Geissler's (2008) distinction.

In terms of my own personal and political values, I took my good intentions towards the wellbeing of the people involved in this study largely for granted. After all, my commitment to them predated, will outlast, and in many ways was the motivation for this project. This, however, creates new problems even as it addresses others.

Negotiating dual roles – searching for a positive ethics and 'impact'

This thesis engages with a series of somewhat abstract questions – such as how disease, suffering and medicine are interpreted, about how HIV changes family structures and personal relationships, and so on. However, it also involves generating and synthesising knowledge about far more concrete issues: have doctors (or indeed a particular doctor) done a good job of making sure patients take their medicines? Is a particular NGO that's attempting to draw people into a treatment programme working effectively? And if HIV positive patients form collaborative societies to exchange expertise and support, how might those organisations be strengthened and improved?

With my previous voluntary work, I was already gathering data and building practical knowledge on precisely these questions long before I seriously considered undertaking postgraduate research. In a sense, it was action-orientated research, without any notion that it was research. I was able to put this knowledge towards immediate, albeit uneven use.

Whilst working within a useful but dysfunctional organisation, my colleagues and I were able to spot problems, diagnose their cause, consider and then implement various solutions. Of course, this linear progression was rarely so neat: more often than not problems were neglected or misdiagnosed, and solutions were either ill conceived or difficult to implement. Much frustration accompanied our occasional successes, but

there was at least a certain degree of clarity to the purpose of my work, if not its outcomes.

Beginning this research as a full-time social scientist, much felt familiar. The places, people, organisations, and many of the issues and practical activities remained the same. In a sense, I was continuing to ask and try to answer many of the same questions about what it means to be HIV positive in Northern Nigeria, but with a different set of professional responsibilities and expectations to fulfil.

This required a very careful form of explaining myself. At the start of research interviews, meetings, and discussions of every kind, I repeatedly emphasised that I was now in a new role, and that I was no longer involved in decisions that could affect their health care or any other services. More carefully developed language to express this helped (see Appendix for examples).

Summary

In summary, the primary methods used in this thesis are ethnography and informal interviews. They are especially used to build biographical portraits of HIV positive people, to trace the events, experiences, and in patterns that are important in their lives. In addition, to explore the political processes involved in trying to secure adequate health care for HIV positive people (and others in medical need), I adopted different tactics, using elite interviewing and institutional ethnography to explore the politics of the state government, doctors, and NGOs.

In this chapter I also reflect on the two specific parts of my methodology that raised uncomfortable and complex questions. I discuss how I used participatory methods in an attempt to make the voices of HIV positive people more central to this thesis. My own experiences and other academic studies, however, suggest that making participatory research (and indeed participatory development) both effective and genuinely empowering is a delicate and uncertain task. This is an approach that requires continuous

attention to both practical and political issues. In spite of these difficulties, my experience with participatory research both produced some interesting empirical insights, and was useful as a basis for thinking through the wider politics of my research project.

This political and ethical orientation is especially important when tackling the topic of suffering. Any study of the ARV era from below is likely to encounter individuals who have suffered or are suffering from significant pain, trauma, and anxiety. Articulating these experiences is vital (and may even be therapeutic for those studied), but doing so requires a careful, sensitive approach. Formal ethics procedures are of little use and relevance in such circumstances, and researchers must independently examine their own approaches and their research setting to devise an appropriate plan. I outline the strategies and self-imposed rules that I developed to try to resolve these issues.

Chapter Three - NGOs, Doctors, and the Patrimonial State – Advocating on behalf of patients in Kebbi[29]

Introduction

The subsequent three empirical chapters each set out different aspects of the ARV era from the perspective of HIV positive people. The extension of these lives, however, depends in large part of the provision of adequate medical care, including of course the drugs themselves. Even when these drugs themselves are provided free or at a much-reduced cost, the state government is still required to organise and deliver this complex treatment.

In other contexts, patient activism – typically through support and self-help groups – has been significant in holding the state to account as a provider of medical care. This was the case in the early days of the epidemic in the West (Dresser, 2001; Maguire *et al*, 2004) and more recently in South Africa (Robins, 2006). KAPOP, the support group for HIV positive people that is important in subsequent chapters of this thesis, at first glance appears to be a political organisation of this kind. Indeed, part of KAPOP's mission statement expresses a mandate to "demand, as HIV positive people, the decent treatment we deserve, through rights-based approaches to issues".

In spite of the invocation of 'rights-based approaches' (which mirrored the rhetoric of an international NGO which supported them), KAPOP was in reality careful to avoid direct political confrontation or even lobbying. This was largely because they were recipients of grants and donations-in-kind that either came directly from the state government, or otherwise required government approval in the form of official registration. Additionally, there

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[29] This chapter has previously been published in edited form as Kingsley (2013b).

was an issue of capacity: KAPOP had no fulltime staff and minimal expertise is politics or lobbying[30].

There were two sets of actors, however, that did apply themselves consistently to this task: doctors, and a handful of international NGOs that maintained a presence in Birnin Kebbi. In this chapter, I explore how they go about this process of lobbying for better treatment. They were interested in improving medical care generally, but many had a specific interest in improving HIV treatment and support. Understanding the strategies they undertake requires reflection on both the history of NGOs, and the nature of Nigeria's patrimonial state. To begin, I review literature that helps open up questions of what it means to be an NGO, and what it is to 'do development' in Nigeria.

Development has been described as a story of initial optimism, followed by disappointment (Escobar, 1994). The reputation of non-governmental organisations (NGOs) has followed a similar trajectory. Much development studies scholarship has attempted to describe, promote, condemn, improve, or leave behind this diverse class of organisations (for instance, Igoe and Kelsall, 2005). The notion that NGOs are uniquely placed to do certain kinds of development work has been tarnished, yet they continue to control significant resources.

Meanwhile, a broad range of scholarship has discussed the various features of Nigeria's political landscape, often emphasising factors that perpetuate underdevelopment and poverty. Nigeria's "intense ethnic polarisation and conflict" (Mustapha, 2005:4), and its "swelling state, feeding political corruption and instability" (Diamond, 1988:33) have created a situation in

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[30] Another VSO volunteer I knew worked for an umbrella organisation for education NGOs in Kano state. She told me that such coalition groups were expected by international donors to critically examine government policy, comment on draft legislation, and so on. In reality, she said, these organisations simply lacked the capacity to keep up with the policy initiatives and implementation of the state government. For all the umbrella group's practical knowledge, it was asking too much of an organisation funded in an ad-hoc way to develop the necessary expertise in lobbying and policy analysis.

which "routine relationships between the state and society [are]…dominated by discourses on the illegitimacy of instrumentalized distribution and disorder" (Gore and Pratten, 2003:212).

Amid declining confidence in some of the key institutions of development and unpromising political contexts such as Nigeria, some actors have called for a more flexible approach, particularly regarding the necessity of 'good government' for development (Hickey, 2012). Scholars such as those working at the 'Africa Power and Politics Centre' have made important progress in exploring what 'development patrimonialism' and working 'with the grain' might entail (e.g. Kelsall, 2008, 2011; Crook and Booth, 2011; Booth and Golooba-Mutebi, 2012). In short, these scholars have argued that certain forms of governance and accountability in sub-Saharan Africa that diverge from Western ideals persist. Given their apparent durability, development actors are obliged, so the argument goes, to work within rather than against such norms. Much work, however, remains to be done in elaborating what these ideas might mean in practice.

This chapter is a review of and empirical contribution to these debates. It presents case studies that contrast different approaches to dealing with one manifestation of Nigeria's political arrangements. The political activities of a large international NGO and medical professionals are described, demonstrating their broadly similar political agendas. Both are attempting to cajole the state government into reforming health care provision, yet they do so with strikingly different tactics and results.

The medical professionals are shown to be skilled political operators, able to use a variety of techniques to extract significant changes from the local government – though not without some awkward compromises. In contrast, the NGO struggles to make the best of its capacity, as it is tied to a set of inflexible and ineffective tactics in its programmes and advocacy.

These case studies suggest that the debate about working 'with the grain' needs to be mindful of both the deep level of expertise that it is often

required to effectively engage with patrimonial states, and the substantial practical and moral risks involved in building partnerships with deeply undemocratic and inequitable systems of government. It also underscores how the successes of the ARV era are often contingent on making highly imperfect government systems work for HIV positive people.

The State NGOs Are In

NGOs operating in Kebbi state do so in a specific political context. The premise of this analysis is that the ability and the willingness to adapt to this context is a key determinant of how influential NGOs can be. Here, conceptual debates about how to describe the patron-client relations in Africa are discussed, as are the specific concepts that are most useful in describing Nigeria's political system. Then, debates about the role NGOs play in Africa are reviewed.

Patrons and clients in Africa

Scholars – especially but not exclusively Africanists – in describing political systems that diverge from Western ideals have developed a set of related, overlapping and sometimes muddled terms, including: 'clientism', 'patrimonialism', 'neo-patrimonialism', 'prebendalism', 'Big Man politics' and 'godfatherism' (for useful overviews, Pitcher *et al*, 2009).

Whilst these concepts have appeared in various guises and emphasise different issues, they all attempt to describe societies that feature both legal-rational forms of government and the informal distribution of patronage by public office holders. Virtually any society matches this description to some extent, but especially so, it is argued, in many postcolonial African states where formal institutions often lack legitimacy (Englebert, 2000).

However, many of these concepts have been strongly challenged. It has been argued that neo-patrimonialism has been applied to so many different cases that it becomes a 'catch all' term with "little analytical content" (Mkandawire, 2013:6); that it is part of an anti-government neoliberal project; or an Afro-pessimist tradition that revels in the misery of the continent (see

Erdmann and Engel, 2007, and deGrassi, 2008, for summaries of these debates). In particular, discussing African corruption and clientelism risks describing social relationships in highly normative, ethnocentric terms, a problem which more universal, neutral terms like 'neopatrimonial' only partly avoid (Blundo, 2006:22; Booth, 2009:9-18).

Furthermore, it has been argued that the concept is often invoked abstractly, without sufficient empirical grounding. Jean-Francois Bayart, one of the most influential Africanist theorists of corruption, has rightly been taken to task for his tendency to assert "definitive positions despite the flimsy evidential material at his disposal", and "to parade innuendo and hearsay as facts" (Mustapha, 2002:3).

Patrimonialism in Nigeria

Consequently, if these concepts are to be invoked at all, it is essential that they are used with precision and with empirical grounding. Daniel Jordan Smith is surely correct when he argues that in Nigeria, "navigating corruption preoccupies people in all kinds of everyday endeavours, and talk about corruption dominates popular discourse" (2007, xiv). Yet these observations are the beginning of an enquiry, not the end, and care must be taken to properly conceptualise and empirically validate such observations.

For this study, it is essential to analyse patrimonialism not merely as a dysfunctional appendage to society, but instead part of "ordinary forms of sociability" (Blundo and Olivier de Sardan, 2006:8); not merely as a form of occasional criminal deviance, but instead a practice "at the core of relations between public services and their users" (ibid:4). Even legal systems, seemingly at odds with practices of informal patrimony, become shaped by them; as Nuijten and Anders argue " corruption and law are not opposites but constitutive of one another" (2007:2).

Richard Joseph's concept of 'prebendalism' (1987) also takes this approach, and is a useful model for this study. Joseph's formulation describes not only the exploitation of public positions by their incumbents, but also the

extensive legitimating practices in which "the appropriation of such offices is not just an act of individual greed or ambition but concurrently the satisfaction of the short-term objectives of a subset of the general population" (*ibid*:67).

Further, he shows how Nigeria's complex and politicised ethnic groupings, its elections, and the distribution of patrimony are mutually reinforcing parts of the same system (*ibid*: especially 30-54). Once the practice of dispensing wealth to secure political support – patrimonialism[31] – is conceptualised as part of a broader political system, important insights become visible. In particular, it emphasises that office-holders must at least "appear [to be] responsive to the wishes of wider sets of people" (ibid:54). This is a crucial opening that, as we shall see, some groups exploit more effectively than others.

If a patrimonial system is indeed pervasive and embedded, political actors might well determine that accommodation is better than confrontation. In this vein, Tim Kelsall's (2008; 2011) formulation of working "with the grain" is a challenge to development actors to move beyond 'good government' orthodoxies and instead "work with the realities of country governance as they find them" (Crook and Booth 2011:101). Booth and Golooba-Mutebi's (2012) on Rwanda's "development patrimonial state" and Alemu and Scoones' (2013) on rural development in Ethiopia both express qualified enthusiasm for such strategies.

However, Kelsall's approach raises various questions (many of which, to his credit, he anticipates), from the exact nature of the 'grain' in question, as to what kinds of compromises and trade-offs might be involved. Exploring the latter, Lisa Denney argues that recent engagements with chiefs in Sierra Leone have been a promising avenue towards security reform, but one fraught with complications and risk when such institutions are

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[31] Or neopatrimonialism: the same, but concealed behind a modern institutional façade.

> *"characterised by inequitable and exploitative practices, recognised by many as a contributing cause of the civil war, yet simultaneously supported by its subjects"* (Denny, 2013:14).

If accommodating patrimonial systems is to be a significant part of working 'with the grain', much exploration of the promises and pitfalls to this approach needs to be done. This study, then, is an assessment of how two particular sets of actors engage with an existing political order. An analysis of their successes, failures and compromises is a way of thinking through the possibilities and limitations of such strategies.

Violent repression

Nigeria became infamous for its violent repression during the Abacha administration (1993-8), not least for the execution of activist Ken Saro-Wiwa in 1995. While things have undoubtedly improved since the return to democracy in 1999, the Federal and State governments nonetheless retain a tendency to intimidate and attack its citizens. Particularly useful for documenting these trends are reports of Human Rights Watch, which distil a range of newspaper and primary sources topics such as the indirect use of vigilante groups in political struggles (2002), the impunity with which security forces maim and injure (2005, 2012), and the relationship between politics, corruption and violence more generally (2003, 2007).

Other issues complicating political advocacy include the long-running conflict in the Niger Delta, a complex series of clashes involving a diverse range of state and non-state groups bound together in an 'informal economy of violence' (Ibeanu and Luckham, 2007:43), and the violent Islamist attacks and equally violent state response (Adesoji, 2011).

In short, parts of the Nigerian state are willing to use or incite violence against perceived threats. It should also be noted that NGOs are by no means excluded from these intimidatory techniques: in 2007, two staff members from ActionAid were detained by the State Security Service (a domestic intelligence agency) in Kebbi, in connection with their role in a

campaign against water privatization (see *Daily Trust*, 2007). Another example of a police/NGO conflict involved a campaign against child-witchcraft related abuse (see SSNCEF, 2010).

This is not to suggest that corruption and violent repression are essential or timeless features of Nigeria. Indeed, Nigeria has experienced rapid change and repeated upheaval in its recent history – decolonisation followed alternating periods of democracy and dictatorship, with successful military coups taking place in 1966, 1975, 1983, 1985 and 1993 (Falola and Heaton, 2008: xiii- xviii has a useful chronology), a civil war in 1967-70, and numerous conflicts, often along ethnic and religious lines (see Sklar 1963 for an early account of these dynamics, or Falola 1998 and Higazi 2008 for more recent examples).

Despite these disruptive trends, patrimonialism and violent repression are notable constants in recent decades. Given that the Nigerian state is prone to using patrimony to pacify certain constituencies, and violence to repress others, advocates of social and political change have to carefully navigate their relationship with the state and employ distinctive strategies in order to achieve their goals.

As outlined in the Chapter One of this thesis, these broader trends are expressed in particular ways in Kebbi. The relevant factors here are the particularly acute poverty that characterises much of Northern Nigeria, suspicion of external (especially Western) interventions, and a closely networked, interpersonal 'small town' mode of governance.

NGOs

The story of NGOs in development is by now a familiar one: a surge of enthusiasm and activity in the 1990s, followed by a backlash of scepticism (Igoe and Kelsall, 2005). NGOs have been criticised in a myriad of ways. They have been accused of depoliticising development, as NGO-based approaches tend to keep "at bay debates about more fundamental structural changes to, say, unequal property rights" (Mohan, 2002:150). Others have

suggested that NGOs often act a comprador class "dependent on external resources and patronage" (Hearn, 2007:1107). Similarly, they have also been criticised as being beholden to Western interests, beset by "structural imbalances that reward upward accountability [and] encourage limited, problematic forms of participation" (Dixon and McGregor, 2011:1372). Continuing this line of criticism, Reimann argues that NGOs are often too reliant on official funding and cooperation, and thus "politically muzzled…shy[ing] away from any meaningful 'empowerment' activities" (2005:43). Commins suggests that this muzzling can even result in NGOs acting as "fig-leaves to cover government inaction or indifference to human suffering" (in Pearce 2000:20). Finally, Dichter argues that NGOs often struggle to sustain a radical or critical orientation, and instead are liable to "act as if they were corporations engaged in the world of commerce" (1999:52).

In summary, both the technical capabilities and political position of NGOs has been subject to comprehensive criticism. Indeed, the legitimacy and effectiveness of NGOs has even received a degree of popular debate. The popular columnist Elnathan John reflected many of these issues in a satirical article entitled 'How to run a Nigerian NGO' (*Daily Times*, 2012):

> *"Running an NGO can be tricky. You rely on the hustle of foreign and local donors. You can suddenly run dry. You do not get a pension. So you must save for the day when donor rains cease to fall or you are too old to get another job. You must learn how to weave in extra items into the budget and inflate project costs. Anyone who calls this stealing, God will swiftly truncate their hustle."*[32]

Given the diversity of organisations calling themselves NGOs, it should not be surprising that such a daunting charge sheet can be assembled. And as Jim Igoe points out, this swing "between exuberance and despair (and

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[32] Similar issues have being raised in the Western media, for instance: 'NGO hopes to benefit from failure', *Guardian*, 17 January 2011, or a recent BBC World Service series (first broadcast 27 December 2011) 'The Truth About NGOs'.

sometimes back again)" (2005:xi) has at least as much to do a wildly inflated set of expectations than with the activities of NGOs themselves.

As potent as these criticisms are, they have by no means destroyed the NGO project. Scholars in the last two decades investigated "the zenith of Africa's NGO revolution" (Igoe and Kelsall, 2005:2) and the subsequent disappointments in real-time. In contrast, the last few years have had a somewhat more mundane tenor: few, it seems, give serious credence to the notion of NGOs as dynamic agents of revolutionary change. However, despite their credibility being badly wounded, NGOs limp on, and they remain so well entrenched in the development system they not only persist, in many cases, they thrive (Ossewaarde, 2008).

Should actors within the development sector, then consider moving on from the NGO era? Or would it be better to attempt running repairs to a flawed but still useful set of organisations? The case studies presented below suggest there is something to be salvaged from development NGOs. However, in this context at least, they may need to rethink their methods of local political advocacy.

Struggling With the State In Kebbi

Why NGOs struggle to fulfil their political potential is in a large part of consequence of their failure to adapt to local contexts. The two case studies here have been chosen to illustrate this. They emerged from a process at the beginning of my fieldwork of mapping out which people and institutions were most active in providing support and care for HIV positive people. It quickly became apparent that aside from KAPOP, the most important actors were government health services and a small group of active NGOs.

Subsequent ethnographic research explored these two groups, which obviously differ in all sorts of ways – the scope and longevity of their interventions, the ways in which they are directed and held to account, the composition of their staff, and so on. Importantly, both the NGO and the

doctors acted as advocates for patients, as intermediaries able to urge the government to do more. Both repeatedly cited their mission to speak on behalf of otherwise weak and silenced patients, and both had frequent opportunities to discuss their concerns with the relevant state officials.

Thus, while the two sets of actors are by no means perfectly symmetrical, they occupy a similar position as interlocutors or brokers within the patrimonial state, and both see this form of advocacy as central to their work. The first case study showcases an example of professionals who are skilful in such interactions, and the second is an ethnographic examination of the nature of, and reasons behind, the self-restricting institutional inflexibility of NGOs.

Case Study – Salary reform and medical professionals

In the time I spent in Kebbi state, the doctors I worked with tended to affect a patrician, paternal, and possessive concern towards *their* patients. As I met with doctors, arranging house visits (during my voluntary work) or asking about a project they were planning, they were often quick to contextualise their work in local politics.

Doctors often offered opinions without prompting on the desperate state of a particular clinic due to the neglect of an official, satisfaction with improvements at another, and comparisons with facilities in neighbouring states. Furthermore, almost every doctor seemed to be in the process of petitioning the state government for support for one project or another. The causes were various, and covered cases that seemed selfless and others that seemed to involve a measure of personal gain: a plea to improving staffing levels in a maternal clinic or to procure new equipment (perhaps from a supplier acquainted with the doctor).

In conversation, doctors repeatedly emphasised that they were responsible for their patients in a broad sense than included political advocacy as well as clinical care. As the following case study shows, this role involves a combination of sincerity, idealism, and compromise. In early 2010, the Kebbi

State Government introduced a new system for paying the salaries of its civil servants. This proved to be a significant controversy, which placed the doctors' role as advocates and brokers at its heart. The state government is a major employer, particularly within the urban centres. This includes teachers, some college and university lecturers, doctors, nurses, as well as various employees of the state's numerous bureaucracies.

The salary change, known as the 'e-payment' system, was introduced by the then Governor Saidu Usman Dakingari, ostensibly to tackle the widespread problem of fraud. It is widely alleged (for instance, *Daily Trust* 2010b, Uchegbu 2011, or more generally in Nigeria; Omotosho, 2011) that senior officials packed government payrolls with family members and associates who hold positions but rarely appear at their offices or complete significant tasks. Others simply hired multiple 'ghost employees'[33] – fictitious persons whose salaries flow back to the corrupt official in question. For those with the clout to set up and conceal them, such scams are highly lucrative – several informants said that such schemes were second only to 'kickbacks'[34] in their profitability.

Opinions were split as to whether the revised system was a genuine effort to root out corruption, or merely a 'changing of the guard' as a new clique took over. Regardless of the motivations for the change (which involved centralising salaries rather than allowing individual departments to disburse funds), the reform process did not go smoothly. An understated government press release referred to 'problems associated with the exercise', meaning the delay or non-payment of salaries for thousands of workers. In May 2010, some had not received their salaries for several months, and many thousands more have suffered various delays and partial payments, issues that took until early 2011 to fully resolve. Interviewees were unanimous in assigning

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[33] The Hausa phrase '*mai katan jabu*' (fake workers) was often used.

[34] Fees paid to officials to award contracts to a particular vendor. The scale of such schemes varies enormously. The former governor of Kebbi state was accused of systematic looting amounting to N10.2 billion (approximately US$68m, *Vanguard*, 2009), whereas one doctor mentioned a colleague's rumoured scheme to supply hospital consumables, which was worth only a few dollars a month.

blame for the problems: powerful officials with a vested interest in seeing the new system fail, and the delays and problems associated were the fruit of their sabotage.

The intricate details of the wrangling matter less than the general issues that the controversy illuminates, especially the manner in which it was resolved. The first is the close relationship between the re-distribution of wealth, and the provision of government jobs. In other contexts, hiring large numbers of workers with little expectation that they will perform useful tasks is an anathema to 'good government', in which 'wasting tax-payers' money' is a grievous sin. Yet the concept of 'tax-payers' money' relies on the existence of a fiscal social contract in which taxes are paid with the expectation provision of services in return. Such contracts tend to be weaker in countries like Nigeria where taxation is low and much revenue flows from natural resource wealth (Moore and Schneider, 2004:especially 6-7).

The problems of poverty and unemployment (especially youth unemployment) are so extreme that hiring workers is seen as an essential duty of the state. Unemployment is also seen as a threat to social order – as one opinion piece in a national newspaper lamented, Governor Dakingari "does not know what to do with huge army of unemployed youth in Kebbi and so they are always available for use in the rising cases of thuggery in the state" (*Daily Trust,* 2010a). There is also a significant ethnic dimension to this process: allocating state resources to Hausa individuals and families was seen as an important responsibility.

Thus, the state government framed the 'e-payment' reform not simply as cutting out corrupt middle men, but also making sure that disbursement was 'correct': that is, amongst a broad spread of the right people, rather than a narrow elite. The state commissioner of finance said in a newspaper interview: "I don't think there should be apprehension over the e-payment system because government [sic] intends to introduce it in order to fish out all ghost workers in the government's pay roll and provide security to salaries of civil servants" (*This Day,* 2009).

As things started to go wrong and payments were blocked, medical professionals taking industrial action in protest were able to reuse this framing for their own purposes. In both private and semi-public meetings, as well as in press statements, they connected their payment issues with concerns over a lack of investment in health care, and especially the ability to recruit and retain health care staff. The chair of the local branch of the Nigerian Medical Association, Dr. Yusuf Sununu, was a key negotiator, and he emphasised to me that "we are all proud people of this state, but so many will be leaving because of the problems [with salaries]". He added that, "Kebbi state has 537 nurses, but up to 80% have [job] interviews at other places [outside the state]"[35].

Despite concerns over the ethics of medical personnel abandoning their posts (Okoye, 2007), such strikes have been common for some time in Nigeria. Alubo's examination of a series of medical strikes in the 1970s and 80s demonstrates that they were remarkably successful in securing concessions, in part because of "a sense of doctors as 'special'" (1986:474).

In this case, the ability of medical staff – and especially doctors – to exercise their privileged position appears to be intact. The medical strike in Kebbi, after numerous delays and last-ditch negotiations, began on 27th December 2010 (*Sun*, 2010). It only lasted a few days, resulting in at least a partial triumph for the strikers. The details of how this deal was resolved are intriguing. In addition to their statements to news media, the doctors were able to leverage their political connections, not least because many were themselves from prominent families.

I knew one doctor[36] particularly well, and would often watch satellite TV at his home in the evenings, as we lived in the same housing estate. He always

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[35] I was unable to verify these specific statistics, but this general situation was confirmed in conversations with many other doctors and officials.
[36] As discussed, political disputes in Nigeria can be highly contentious and unpredictable, so as with other individuals in this thesis, the doctors quoted are not

received a steady stream of guests in the evening: colleagues, family friends, and patients seeking out-of-hours advice. For these guests, he always kept a stethoscope and a pad of prescription forms on the table, and a fridge stocked with soft drinks. During the strike, his living room became something of a nerve centre for negotiations. Although the doctor was not an official negotiator, his seniority and political connections made him an important broker.

The tone of these discussions, or at least the ones in which I was present, was strikingly cordial. Emissaries from the state government would arrive, and linger over customary greetings in a particularly deliberate fashion – lamenting the recent passing of a mutual acquaintance, or asking in turn about each other's relatives. The content of the discussion too – despite ostensibly being about a deadlocked labour dispute – emphasised consensus.

A shared narrative of health care in the state was often retold – a story I heard again and again in different forms from almost everyone I spoke to. Health care services when Kebbi state was created in 1991 were extremely basic, and had remained parlous for much of the following decade. Significant improvements had been made since then however, and Kebbi citizens took pride in the fact that fewer patients felt the need to travel out-of-state to receive good care.

A key bargaining chip for the striking doctors was their ability to either endorse or tarnish this narrative of accomplishment. When I asked one doctor about a negotiation he had attended late the previous evening, he said he had told one of the governor's senior aides that they "always tell people how far we [the people of Kebbi] have come, and how the governor has always been our friend". Within the compliment was an implied threat that the doctors might withdraw their valuable support should the dispute not be satisfactorily resolved.

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identified, with the exception of Dr. Sununu, the union representative, who asked to be identified.

"We really reach down to the grassroots" said the same doctor. "Everyday at the hospital I see people from every nook and cranny of the state. They are all my people". Like the Malawian civil servants Anders describes, much of the potency of the doctors lies in their ability to manage "widely branching networks; bridging huge differences in social position and location" (2002:2).

Doctors and the state governments were frequently at loggerheads over particular issues, but they shared a strong pride that Kebbi was making great strides forward. Even those doctors who were disappointed with Governor Dakingari and his predecessor Muhammad Adamu Aliero nonetheless tempered their criticism – both in public and private – by acknowledging the progress that had been made.

In this context, a shared loyalty to Kebbi was a powerful motivator. At the end of a long conversation in my doctor friend's living room, mostly in Hausa, a state Ministry of Health official, said to me in English: "We are not going to any other place, we cannot run away to Lagos or Kano, so we have to make a solution". In such meetings, doctors made clear how seriously they viewed the salary problems and other issues, but also emphasised their loyalty to the governor and the state. For example, in one meeting, a doctor made a lengthy speech lamenting the fact that a trial scheme to train traditional birth attendants in techniques for preventing mother-to-child HIV transmission had petered out, instead of being expanded. The criticism was passionate, but never personalised to a particular official, or indeed the governor. This combination of pressure from an embarrassing disruption in health care services from the strike (especially acute as gubernatorial elections took place four months later, in April 2011) and discreet, non-confrontational lobbying proved highly effective.

A salary deduction that made state employees' net salaries significantly lower than that of comparable Federal Employees (a source of irritation repeatedly mentioned by the strikers) was suspended. 'We have been assured that the demand for reduction on taxation of our members and implementation of policies that would reduce the exodus of medical workers

and better conditions of service would be met", said Dr. Sununu in a public statement (*Tide,* 2011). One doctor put it more bluntly, echoing a popular sentiment among doctors when saying: "We got 90% of what we wanted".

The lessons are clear. Medical professionals, and especially doctors, demonstrated that by formatting claims in a particular way, and by using social networks and political expertise sensitively, they were able to extract significant concessions. It is important neither to exaggerate nor to underplay these accomplishments. Their actions involved both challenging the patrimonial system, but also working within it. Doctors emphasised how substantive improvements were necessary, and it was not sufficient to buy-off constituencies with promises to build a new clinic or hospital. Nonetheless, in other ways, they accepted and reaffirmed the logic that the governor's role was to be a provider for his people, and they talked about his 'generosity' and 'kindness'.

This example suggests that when the state government is in one sense resilient and able to partially deflect popular disaffection by making commitments that are partly substantive and partly symbolic. Yet it is a form of resilience which savvy groups are able to exploit.

There is a moral ambivalence to the doctors' role. On the one hand, doctors cannot transform Kebbi's political system, and in many cases work effectively 'with the grain' to encourage incremental improvements. On the other hand, this mode of engagement often brings the doctors into the unenviable position as apologists and defenders of a government that is far from perfect. This is a particularly awkward situation with an issue such as salaries, which inevitably combines altruistic reform with elements of self-interest. The flexible role of the doctors, however, takes on a more respectable sheen compared to the less effective strategy of a large NGO.

Case Study – Health For All

A broad range of NGOs exist in Kebbi state. Even within the thematic area of HIV/AIDS, some thirty-eight local organisations are listed as active

according to one directory (unpublished document, Civil Society for HIV/AIDS in Nigeria, 16 August 2010). In addition, a number of national and international NGOs work in Kebbi – including well-known organisations such as ActionAid and Médecins Sans Frontières. Of the smaller NGOs (often called 'community-based organisations'), KAPOP and several others provided a significant level of care, but over the course of my research most appeared to be largely inactive. But for this chapter, the focus is on larger NGOs: typically either international bodies, or at least part of international networks of funding and expertise.

These organisations are uniquely placed to contribute to political, economic and social reform in Kebbi yet are often, by the admission of their own staff, frustrated and marginalised. I studied several such organisations, but the most relevant for this study is an organisation referred to here as Health for All[37] (HFA). HFA works in several African countries, has an office in Nigeria's capital Abuja, and runs programmes in several Nigerian states. Over four months in HFA's Kebbi programme office I sat in on meetings, travelled to visit distant projects and participated in various workshops. In many ways, the organisation met the stereotype of a big international NGO: large white Landcruisers parked in the office's walled-off compound, regular meetings conducted with participatory techniques, and the omni-present development jargon of 'stake-holders' and 'capacity building'.

HFA had a striking concentration of well-qualified and capable staff. Almost all of HFA's employees, even lowly administrative staff and drivers, were graduates, often from Nigeria's most prestigious institutions. Many of the senior staff had studied abroad or worked abroad, or were studying expensive postgraduate distance learning courses at British or American universities. Several were qualified and experienced doctors.

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[37] The decision to conceal this organisation behind a pseudonym is a difficult one, as identifying it would add useful contextual information. However, given that frank private views are reported it is necessary, as with the doctors, to protect research participants from potential professional and political consequences.

Almost all of HFA's staff also shared a passionate and often highly informed interest in politics. Over lunch, on a long drive to a rural clinic, or after work – conversation invariably turned to political issues, discussing both the fates of various local politicians or parties, and making sense of broader issues in Nigerian society. Most were idealistic, and lamented the current state of Nigeria – often saving me a newspaper cutting, or sharing a link to a cartoon on Facebook to make a point.

In short, HFA was staffed by an educational and intellectual elite, voracious in their appetite for political news in all forms, and sophisticated in their understanding of issues. Additionally, the projects that they had been tasked with delivering – a variety of activities related to HIV treatment support – emphasised the need for engagement and advocacy with the state government. The proficiency of this staff, in combination with their access to international capital – that is to say the funding for their project – would seem to make them well placed to engage with the Kebbi state government. HFA staff also had extensive contact with state government officials at a variety of levels. They attended the regular meetings of the State Action Committee on AIDS (SACA), a statutory body responsible for coordinating HIV treatment and prevention. Additionally, HFA ran several projects that took place within state facilities, such as a drop-in counseling service for HIV positive people being run at several regional hospitals, which involved frequent meetings with officials.

Nonetheless, a highly cautious mode of political engagement predominated. In private, HFA staff complained about the state government. Out for drinks after work, the staff would trade stories of the poor condition of a hospital, an incompetent official, or an ill-conceived project. A particularly common complaint was the government's perceived preference for big capital projects like hospital construction – which was seen as both a political strategy to show demonstrable progress, and an opportunity for corruption during the construction process. These eye-catching projects came at the expense, so they argued, of more mundane activities like staff recruitment and training. They also expressed concern that state hospitals were struggling to retain

qualified staff, largely due to low wages. In short, HFA staff broadly shared a reform agenda with the medical professionals. They also emphasised their role as advocates on behalf of patients. One HFA officer, a medical doctor, explained why he had chosen to work for an NGO rather than practice medicine: "When I first qualified, the HIV situation was very bad. Patients were afraid to come out, and the government was doing nothing about it. That is why we doctors have to be politicians."

Yet during the meetings they had with senior officials, this zeal for advocacy was conspicuously absent. Pleasantries and mundane procedural issues predominated, and it was clear that certain topics, especially corruption and spending priorities were off-limits. When asked about this tension between idealism and political neutrality, HFA gave somewhat contradictory responses: "The political situation here is quite difficult, we need to be quite careful" said one member of staff. Yet in the same conversation, the blame was directed towards HFA itself: "Even the director [of the HFA office in Kebbi] is not really the director, our programme is all planned for us before we arrive." Another said "at the SACA meetings, we are always being asked for something, and you know, these are very good ideas - some small workshops or something, but our hands are tied, we cannot freelance". In short, they attributed their reticence to two factors: one was a pragmatic understanding that state government was ultimately a gatekeeper to their work, and they relied on its consent to continue. To be told to leave would be a professional disaster for the senior staff.

The second constraint – a subtle but powerful factor – was a pervasive form of upward accountability. A particular phrase captures this issue: '*it needs to be sent to Abuja'*. The 'it' being a report, form, spreadsheet or other document, and 'Abuja' meaning HFA's head office. Among the staff, the phrase was repeated almost mantra-like, to the point where its common usage became an in-joke.

For instance, HFA began a round of workshops training volunteers to give advice on drug adherence counselling – sessions to encourage patients to

take their anti-retroviral drugs correctly, long recognised as a complex and important issue in HIV treatment (e.g. Rao *et al*, 2007). It quickly became clear to both the HFA staff and myself, as I sat in on these sessions, that the training was at too basic a level, and largely unnecessary as most of the participants had clearly already been well schooled on these issues at previous events[38]. This may well be in part because these particular treatment-competent groups tended to contain few of the younger patients that are seen as especially challenging for drug adherence (Falang *et al*, 2012).

Many participants suggested that instead of doing these superfluous workshops, could HFA not support the volunteer counsellors in a more practical way – for instance, by providing a small, regular transport allowance to allow those in rural clinics to fetch drugs from the city? Or by offering more specific treatment support – dietary tips, or advice on managing particular drug side-effects perhaps? HFA could not. The worksheets and detailed programme specifications had locked the HFA staff into inappropriate activities, preventing even minor deviations from the schedule.

Another example illustrates the costs of HFA's rigidity in a different setting. A group of doctors at one of Birnin Kebbi's main hospitals were planning a one-day workshop also on anti-retroviral drug adherence, this time as training for counsellors. Serendipitously, two HFA staff members had run a similar course elsewhere in Nigeria. The group of doctors approached HFA with a plan to expand the course to include a more detailed curriculum, more participants, and with sessions in smaller groups to take advantage of having more training staff.

The doctors – who had a strict budget of their own – suggested that HFA contribute to the cost of the workshop by paying the *per diems* for half of the thirty proposed participants, with the hospital budget covering the other half

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[38] There is a subgroup of HIV positive patients in Kebbi with a significant knowledge of various aspects of ARV treatment. They certainly qualify for Kielmann and Cataldo's (2010) definition of 'experts patients', who are increasingly significant in ARV provision in Africa.

as well as the venue and other costs. These *per diems* would have been a very modest sum (perhaps US$50-70 in total) but again HFA regretfully declined the offer as the local staff had no discretion to authorise the spending.

Again, an opportunity to complete productive work that was in line with HFA's stated agenda was spurned. More consequentially in the long term, a chance was missed for hospital doctors and HFA staff to strengthen relationships, and creating future opportunities to work together. I asked one doctor who told me one version of this story if HFA was particularly bad. No, he replied, the behaviour was typical – other NGOs are even worse because "at least [HFA] are talking to us, and I can always reach them [on the phone], the others will not pick my calls – but still [HFA] are not joining us".

In a setting where corruption is such a serious problem, it is perhaps a little churlish to object to this forensic mode of accounting. But as Harsh *et al* (2010) have shown elsewhere, this mode of accountability has consequences beyond being merely a cumbersome administrative burden. It profoundly limits what can take place, and at worst can create organisations whose sole "mission [is] to provide accounts — financial records and success stories" (Harsh *et al,* 2010:274). HFA staff openly acknowledged and lamented their self-imposed marginality. One said: "Of course, I would like to say more things [to the state government], and do something of the things they are asking for, but that is not what we do". Many staff members, it seemed, were willing and able to work 'with the grain' if allowed off the leash.

Individually, these examples may seem trivial, and reflect working practices flawed in a rather obvious manner – they were certainly obvious enough to greatly frustrate all parties. Taken collectively, however, the pattern across the organisation, aggregated to form a reliably wasteful way of operating. "These NGOs are always going to do their own small-small things", said one doctor, expressing a common acceptance that NGOs were almost wilfully marginalising themselves. Tellingly, when I discussed my impressions with doctors, workers at other NGOs and others besides, no one ever seemed

surprised. Instead, people nodded with wry smiles of familiarity and frustration.

Summary

Even though the professionals discussed in this chapter pursue similar goals, move in similar circles, and indeed often know each, they act through strikingly different strategies. The doctors are nimble enough to exploit opportunities (such as upcoming elections) and sufficiently deft to blend occasional confrontation with supportive engagement. They are skilled at moving between roles and registers – one day the dutiful supporter of the government, the next a public-minded physician ready to raise the alarm for his imperilled patients, the day after that, dutiful once more. They read the political situation skilfully, and are able to "capitalise on clientelism and rule-flexibility" (Kelsall, 2011:255).

Yet flexibility in tactics implies a concomitant flexibility in ethics. Their tactics can be and are used both for the benefit of themselves, and for the broader public good – sometimes at the same time. This places doctors in an ambivalent position regarding the patrimonial state – the line between incrementally improving things and endorsing the status quo is fine one. They cannot be said to be meaningfully subverting or undermining it. It is plausible that the immediate gains they are attracting make more radical future improvements more difficult. But in light of the durability of patrimonialism as a political system in this context, it appears that going 'with the grain' is indeed the only effective strategy for encouraging reform.

The NGO, and others like it in the area, orientates itself towards the state very differently. The local expertise of the NGO staff is subsumed by an internationally driven mode of working that precludes the kind of strategies used by doctors. Research elsewhere suggests that this situation is by no means unique, with supposedly progressive organisations dominated by "management tools concerned with enforcing and regulating" (Powell and

Seddon, 1997:7), or worse "apolitical institutions geared toward the process of donor funding cycles" (Igoe, 2003:863; see also Harsh *et al*, 2010).

Could such an NGO find developmental opportunities even in a political system that is a major cause of underdevelopment? Perhaps so, if they were willing to experiment with more flexible forms of accountability, ones which blend necessary rigour with discretion devolved to local officers (see Routley, 2012 for a compelling example). Being able to improvise and adapt, and engage in petty *quid-pro-quos* could help build the "formal and informal channels of access to key political decision-makers" (Bratton 1990:116) that are so crucial to effective advocacy.

Further exploration of what it means to work 'with the grain' will likely emphasis the context-specificity of the issue. The sheer variety in the nature and permanence of patrimonial states will lead to different conclusions than those presented here. In other states where institutions are evolving in different ways, a 'good governance' agenda and straitlaced NGO strategies may be far more appropriate. Elsewhere, in places more like Northern Nigeria, devising a mode of working that balances the understandable need of donors for clarity and accountability with complex, unpredictable, and ethically murky realities will remain a formidable task.

HIV positive people in Kebbi are to a certain extent fortunate that they have doctors as relatively effective advocates. But the absence of HIV positive people themselves from the process of advocating for treatment is conspicuous. In other areas of life, however, HIV positive people are able to exercise more agency. The subsequent chapters explore the extent and limits of this agency, beginning with the ways in which HIV positive people understand and attempt to alleviate various forms of suffering.

Chapter Four - HIV, suffering, and the ARV era

"People forget that HIV decimated the immune system – but people actually died from the opportunistic infections. These 'OIs' were something out of Dante's Hell. So many drowned to death from pneumocystis. Or they would develop hideous KS[39] lesions, or extremely painful neuropathy (my "buddy" screamed once when I brushed a bedsheet against the tip of his toes), or CMV[40] where a friend of mine had to inject himself in the eyeball to prevent going blind, or toxoplasmosis, a brain degenerative disease where people wake up one day to find they can't tie their shoe-laces, and their memories are falling apart…Once you knew your T-cells were below a certain level, it was like being in a dark forest where, at any moment, some hideous viral or bacterial creature could emerge and kill you. And for fifteen years there was nothing to take that worked, just the agonizing helplessness of waiting to die, and watching others get assaulted by one terrifying disease after another."

Andrew Sullivan (2012), on the experience of HIV-positive people in the United States in the 1980s and early 1990s.

Introduction

Suffering is frequently central to descriptions of what it means to have HIV. As the US-based political blogger Andrew Sullivan - himself HIV positive – vividly describes, the conditions that follow from a weakened immune system can be unpredictable, bewildering and nightmarish. Yet these physical symptoms are merely one manifestation of a whole series of pains, fears, and indignities that HIV can cause.

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[39] Kaposi's Sarcoma, a tumour caused by a virus. It is worth pointing out that opportunistic infections vary by region. Whilst common infections rapidly killed millions in poor countries, in the West these could be more easily treated, and HIV positive thus tended to be afflicted by a different set of conditions. I am grateful to Dr. Mike Kesby for this observation.

[40] Cytomegalovirus, a virus similar to herpes.

This thesis is about the multiple consequences of the rise of the anti-retroviral era in Kebbi. Each of the empirical chapters explores important aspects of this – changes for NGOs, for livelihoods, for romantic relationships, for the local government and so on. But in a sense these are all second-order changes. This chapter focuses on the direct consequences of these pills: unassuming in plain white cardboard packaging, but far reaching in their effects. When taking or seeking ARVs, some dimensions of suffering HIV positive people experience might be reduced. Other dimensions of suffering are altered in some way, but are rarely erased altogether.

Changes in the ways that people suffer in the ARV era is, in many respects, the necessary starting point for discussing the impact of anti-retrovirals. In a narrow sense, the effects of taking ARVs are straightforward – supressed CD4 counts, a maintenance or revival of health and weight, and life stretched out over many more years[41], at the cost of the drugs and a few irritating side effects. Yet there is much more to health, illness and suffering than this. Even in the pre-ARV era, the trajectories of HIV positive patients were varied and unpredictable. But too often, these stories had a predictable final act – a decline in health, with respite periods of good health becoming progressively shorter and less common, and finally death.

The HIV positive people I knew over five years were facing a new future, one in which long-term good health was an exhilarating possibility. Nonetheless, their futures were precariously balanced on a series of uncertainties: the continued availability of drugs and the means to get them, the potential for drug resistance, and the continued social complications of living with HIV. Suffering remained stubbornly present for these people. Suffering could continue unrelentingly, or be joyfully suspended,

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[41] The most recent UNAIDS (2013) report notes that "in 2011, life expectancy in the KwaZulu-Natal province of South Africa was 11.3 years higher than in 2003, when HIV treatment scale-up began" (*ibid*:48), and that worldwide deaths from HIV have fallen from 2.3m in 2005 to 1.6m in 2012.

remembered from the past, or feared for the future – but never left behind permanently.

A roadside sign in Birnin Kebbi. 'Come and take medicine for HIV/AIDS, it's free'. Photograph taken in December 2010.

The rapidly expanding availability of ARVs is of course an enormous net positive. It has been claimed for some time – with merit – that the ARVs have re-categorised HIV from a deadly disease to a chronic one (e.g. Scandlyn, 2000; Siegel and Lekas, 2002; and more recently Deeks, Lewin, and Havlir, 2013). Yet this simple formulation conceals the profound, complex and continuing suffering that must be endured, processed, understood and resisted by HIV positive people.

This chapter reviews social scientific and especially anthropological perspectives on suffering, in search of an agenda and vocabulary suitable for the task. I explore how suffering has been treated in its social dimensions, how it can be elusive, and difficult to articulate, how suffering can be

experienced as dehumanising or depersonalising, and finally how suffering might be used or repurposed as a spur to self improvement.

It is these reflections on suffering provide a foundation for discussing the methodologies and ethics of conducting this kind of research (as I do in Chapter Two). Here, I use these insights to discuss a series of ethnographic case studies that highlight the different forms, presentations, and trajectories of suffering that are central to the experience of HIV in the ARV era. These suggest that life with HIV can be an isolating experience, where the city around a person becomes less hospitable and navigable. For others, the suffering is less spatial than it is temporal – past traumas and fears for the future predominate. It is also shown that organisations like support groups, purportedly well intentioned, can unfortunately operate according to logics which make a suffering body a necessity. While the data for all the chapters in this thesis was collected concurrently, in terms of the narratives of individuals concerned, this is the first story, to which the others are sequels.

Suffering and the social sciences – literature review

There is a strong *prima facia* case for making suffering a subject of this inquiry. Most straightforwardly, it was a topic, and indeed a word mentioned repeatedly in conversation: 'at the end of her life, my God, she was really suffering[42]', or 'because of that journey [to collect medicines] my suffering got worse'.

For those living with HIV in Kebbi, suffering is a negative experience, though one which is not limited to physical agony. There is the inconvenience of repeated trips to the hospital alongside the frustrating itch of a skin complaint. There is the immediate burn of disgrace when a previously close friend fails to answer their phone, and the slow-burning dread of contemplating a lifetime of dependence on toxic drugs. Suffering

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[42] 'Suffering' finds a ready translation in Hausa – 'wahala' can refer to both petty and major strife, and also can infer struggle or difficulty – e.g. 'ina shan wahala saboda na biya kudin makaranta' meaning 'I'm suffering just to be able to pay my school fees'.

encompasses the palpable and the abstract, things in the present, but equally those in the past and in imagined futures.

In his monograph of the sociology of suffering, Wilkinson notes a number of paradoxes in the social scientific study of suffering. On the one hand, it is a fundamental topic of social research – subjects such as poverty, violence, inequality and so on are all anchored by an understanding of the importance of human suffering and its alleviation. Yet at the same time, these same subjects can elide the specific nature of suffering. 'Poverty', say, is a proxy whilst "the actual quality of the lived experience of suffering rarely appears as the direct focus of sociological study" (Wilkinson, 2005:2).

For Bryan Turner, a lack of direct engagement with suffering is a subset of a broader neglect of the body, which "constitutes an analytical gap at the core of sociological enquiry" (1996:60). (For Turner, the omission is present across the social sciences, but is especially pronounced in sociology.) Suffering belongs to both one's body and to society. Therefore, the complex role of our flesh is brought to the fore: "The body is at once the most solid, the most elusive, illusory, concrete, metaphorical, ever present and ever distant thing - a site, an instrument, an environment, a singularity and a multiplicity" (*ibid.:*43). Thus, foregrounding suffering goes hand in hand with foregrounding the body.

Similar theoretical interests in the body have evolved in human geography. Research has investigated previously neglected topics in "body–space relations such as smells, tastes, gestures, reactions, clothing, glances and touches" (Longhurst, Ho, and Johnston, 2008:208). There is also a methodological debate, with Mike Crang's much-cited article making the case for the "body as [an] active agent in making knowledge" (2003:499) during the research process (see also Paterson, 2009, on 'haptic geographies'). Importantly, the many and varied relationships between the body, self, and the environment are not static, and experiences such as suffering can re-order them. One such example might be a long and arduous walk, during which:

The painful, footsore body is externalized from the self, and shimmers into view as a problem to cope with. (Wylie, 2005: 244)

Important discussions are on-going about the nature of the body in the geography of emotion, and the related (though not identical) field of the geography of affect (Pile, 2009:11, see also Curti *et al*, 2011). This sub-discipline serves as a valuable reminder: the suffering of the body, suffering in social relationships, and the suffering of the self will often overlap, interlace and affect one another, sometimes in unexpected ways. For the present study, what needs to be explored is the link between the embodiment of suffering, and the kinds of relationships that emerge in and through suffering. I begin here, then, by introducing the theory of social suffering, and then considering the characteristics that are attributed to social suffering. Existing literature reveals the complexity of suffering, but also points to the difficulties that emerge when attempting to categorise suffering.

Social suffering

Bodily and non-bodily suffering are often closely intertwined for the people in this study. The most influential articulation of this line of thought in medical anthropology has been the concept of 'social suffering', foreshadowed by Arthur Kleinman (1988) in his work on illness narratives, and later expounded in a monograph co-authored with Veena Das and Margaret Lock (1997). Here, a series of examples demonstrate that individual and social problems are not merely complementary and reinforcing, but also constitutive of one another.

The combination of 'illness narratives' and 'social suffering' is important, as often it is over time that the relationship between the social and physiological becomes especially complicated. Turner, for instance, cites the example of gout – which may start out as a straightforward complaint, but may become a personal feature, recognisable through an altered gait, perhaps even a badge of honour for a leisurely lifestyle:

The external disease becomes part of culture and personality through appropriation and interpretation. This Groddeckian perspective may appear peculiar, but it is an important corrective to some of the literature on sickness which fails to grasp the contradictory, dialectical nature of suffering. (1996:223)

The primary advantage of the social suffering approach is that it broadens out a narrow, medical perception of a patient's health to a more holistic perspective. In considering how other sources of distress can compound, interact with, and reframe physiological pain, the technical field of medicine becomes more politicised. Indeed, this was part of Scheper-Hughes manifesto for her discipline, arguing that what was required was an "alternative and *critically* applied medical anthropology need first of all to disengage itself, dis-identify with the interests of conventional biomedicine" (1990:192, emphasis in original). This move of politicisation has been helpful to "link health problems with social problems, and individual with collective experiences: in conflict settings, they place social, cultural, political, and economic matters at the forefront of public health concerns" (Eggerman and Panter-Brick, 2010:72).

This points to a central theme in this chapter, and indeed this thesis: in the ARV era, HIV positive people continue to suffer. But the way that suffering changes, and certain forms of suffering sometimes reduced, is often only partly related to the benefits and side-effects of treatments; changes in suffering might instead be thought of as emerging from active strategies – personal, social and political, that people use to reduce their suffering.

Suffering as elusive

Suffering is an important label to apply to a set of experiences that reflect the personal and social. Yet it is often one that is difficult to precisely affix to an individuals experience, in part due to the notion that suffering is profoundly subjective and perhaps incommunicable:

While being able to recognize and respond to the outward signs of a person's distress, we can never actually enter into the realms of their personal experience of suffering…There may be no symbolic forms of culture that are adequate to represent all the ways in which suffering may afflict our humanity. Perhaps we ask too much of our capacity for language when we seek to represent a phenomenon which appears to be so dynamically adapted to the purpose of negating every aspect of our being? (Wilkinson, 2005:17)

Acknowledging the elusive nature of suffering, Byron J. Good nonetheless challenges "the assumption that experience is subjective, belonging to the 'dark grottoes of the mind', and therefore ultimately unknowable" (1994: 117). Similarly, William Connolly has argued that attempts to tame and process suffering are always likely to be incomplete:

We organize suffering into categories to help cope with it, but often these categories themselves conceal some forms of suffering, even contribute to them. This latter experience leads some to suspect that suffering is never entirely reducible to any determinate set of categories. (Connolly, 1996:251)

As a methodological strategy to witness this elusive experience, Good draws on the phenomenological tradition. His goal is to understand the experience of pain, in its "sensual modalities" (1994:123) as well as illness narratives to reconstruct and retell the worlds of those who suffer. Consequently, in the ethnography presented below, attention is focused on the physical symptoms of pain, but also how people talk about those symptoms, and the connections they make with other aspects of life. In particular, the ways in which they feel that their futures are constrained – itself a form of suffering – is discussed as an indirect but potent form of suffering.

Andrew Irving's (2005) descriptions of HIV positive people in Uganda and New York are an inspiring methodological model. Irving is sharply attentive to the bodily consequences of living with HIV, describing the deteriorating sight of a former photographer and the unpredictable fatigue of an urban

farmer. But he also foregrounds how this bodily suffering is inextricably linked with social anxiety:

> *The suffering and uncertainty caused by HIV/AIDS has a 'volume' that extends out from the person and fills up the entire room, house and even seeps out into the neighbourhood. If you ask Yudaya's children they will tell you how it felt to dwell in the midst of their father's death; they'll talk about how this atmosphere descends every Christmas and how this last Christmas they kept imagining their mother's impending death.* (Irving, 2005:322)

He proposes a theoretical framework that emphasizes how individuals must 'reinhabit' their bodies and ultimately their lives after the disruption of a chronic illness. More powerful, however, is Irving's effectiveness of style. It illustrates the possibility of expressing suffering through narratives that are complemented by thick description, and which fully engage and reference a range of senses and emotions. His work points to the unique power of the ethnographic method, which does not require categorisation in order to describe and explain. The mess and complications that come with rebuilding a life after HIV, and the obscure, inarticulable nature of suffering mean that the experiences related here cannot be readily abstracted, and translated into fixed formulae and patterns.

Suffering as dehumanizing

There are two further and highly contradictory aspects to suffering which are apparent in the literature and in this ethnography. They concern the power of suffering to cripple someone to the extent that they start become 'dehumanized', and the opposite possibility that suffering can be repurposed as a spur to personal improvement.

The process of 'dehumanization' is most familiar and dramatic in violent situations, where the humanity of an individual, or more often an ethnic or religious group, is denied enabling them to be treated as animals or inanimate objects (Kelman, 1973). Another more quotidian example is the

tendency of doctors to detach themselves from the human experiences of their patients, instead seeing and treating them in mechanistic terms, which Haque and Waytz argue is largely a result of the "structural and organizational features of hospital life, as well as from functional psychological demands intrinsic to the medical profession." (2012:176; see also Barnard, 2001). These perspectives emphasise interactional dehumanisation. Another possibility is that pain and suffering, especially over the long-term, open-ended experience of chronic illness, strip the individual of those "characteristics that are uniquely human and those that constitute human nature" (Haslam, 2006:252).

In either circumstance, processes of dehumanization might require the collaboration of others. João Biehl's study of a young woman suffering from elusive but crippling psychiatric and physical symptoms provides one such example. Throughout the course of her treatment, Biehl' subject[43] Catarina's various bodily pains were dismissed as part of a psychosis – she had been stripped of the competence to describe her own body. Through psychiatry, "her inner life [was] restrained, annulled, even beaten out of her." (2005: 150) Catarina thus becomes 'depersonalised', rather than dehumanised – she is not treated as an animal or an object, but the relationships and sociality that constitute personhood (Riesman, 1986) are nullified.

However, in other situations, suffering itself might be the only other presence, acting within or upon the body. For patients suffering from overwhelming physical pain for instance, such as Good's interviewee Brian, the threat that an individual's humanity may be overwhelmed comes more directly from the pain itself:

> *The pain has agency. It is a demon, a monster, lurking within, banging the insides of his body. Pain is an "it" which "erupts in various places in your body," a force which streaks around the body, which Brian seldom feels able*

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[43] Perhaps ingénue or muse is a more suitable term, given his captivation with her life and poetry.

> *to control... the body itself becomes personified as an aversive agent.* (Good, 1994:124)

Thus, suffering in extreme cases is not merely an inevitable part of being human, but a threat to it. It might constitute a threat to an essential level of human dignity (Pullman, 2002), either through the rejection of the suffering body by another as being fully human, or through the degrading effects of pain which strip some of the features associated with being human, including the ability to express pain in a way that others might empathize with (Olson, forthcoming). In the specific case of this study the potential for dehumanisation is two-fold: the threat of stigma to vital relationships, and the threat of pain to bodily autonomy.

Suffering as 'reparation'

Conversely, a further important notion is that suffering can be a positive, formative event. The subsequent chapter explores the most significant manifestation of this process, arguing that HIV can be a spur for reconfiguring romantic expectations and experiences. However, there are various ways in which the suffering that follows from HIV can itself become a trigger for various forms of personal revaluation.

Bury argues that in the West, as disease burdens have shifted away from infectious diseases and towards chronic ones, notions of personal reinvention have become prominent, as "patients' stories speak to illness as a form of disruption that can be turned into self discovery and renewal" (Bury, 2001:276).
Such patients' stories often make use of self-help literature (which I explore in greater depth in the subsequent chapter) or religious arguments of various kinds. Fortune adds that religious narratives of redemption are extremely common, including suggestions that suffering:

> *'builds character' or is 'a test of one's faith'. The purpose of suffering then is the lesson it teaches, the result should be a stronger faith in God.*

Purposefulness somehow softens the pain of the suffering. If some greater good is salvaged, then perhaps the suffering was worth it (1995:87)

Whilst Fortune (*ibid.*) notes that the lay expression of religiosity and suffering are often vague, formal Christian theology has also addressed the topic. For instance, the Belgian Catholic theologian Edward Schillebeeckx conceptualised suffering as not just a burden to bear, but also a spiritual resource. As McManus summarises, for Schillebeeckx, "suffering is so tangibly present in human experience, it provides the means, dialectically, of imaging the horizon of our hope. [Therefore] salvation can be articulated only in counterpoint to the reality of suffering" (1999:477).

In a study of the spiritual beliefs of advanced HIV patients, Hall makes a similar argument, again noting a dialectic relationship, in this case one in which "suffering informs spiritual meaning, which in turn ameliorates suffering" (1998:143). More broadly, Max Weber (1958), famously identified a willingness to embrace ascetic suffering as a key driver behind the Calvinist work ethic.

Friedrich Nietzsche offered a comparatively secular argument about the benefits of suffering. Drawing on his own experiences of debilitating illness, Nietzsche wrote:

I have often asked myself whether I am not much more deeply indebted to the hardest years of my life than to any others … And as to my prolonged illness, do I not owe much more to it than I owe to my health? To it I owe a higher kind of health, a sort of health which grows stronger under everything that does not actually kill it! – To it, I owe even my philosophy … Only great suffering is the ultimate emancipator of the spirit … the suffering that takes its time – forces us philosophers to descend into our nethermost depths … (Nietzsche, 2011: 79, cited in Olson, forthcoming:15)

For Nietzsche, as Olson summarises, "even extreme forms of suffering…can produce valued outcomes in individual or social development" (*ibid*), a position similar to Davies' notion of "productive suffering" (2012).

Whether inspired by religious doctrine or profane secularism, expansive possibilities exist for turning suffering toward a positive purpose. Reviewing a broad range of patient narratives, Arthur Frank considers what it might mean to go beyond Talcott Parson's (1951) notion of fulfilling a 'sick role', and instead becoming 'successfully ill'. He argues that "suffering becomes endurable when it is encompassed within a vision of possibility. It is possible to *use* illness." (Frank, 1997:143, emphasis in original). The possibility of suffering is not limited to academic reflection, for it can also be found in fictional works. A survey of novels and short stories that feature HIV highlights that even the passing of loved one is often a springboard:

> "Death and mourning are figured not as opportunities to blame or conclude stories…but as times to begin the process of renewal. Death is depicted as a catalyst to individual change and development, through the revelation of knowledge" (Attree, 2010:85).

The ethnographies presented below suggest a variety of ways in which people have made *use* of their suffering. The task is to clarify and explore how the particular suffering that HIV has wrought has disrupted lives, how such suffering has been, on occasion, remade and reused.

Summary

The term suffering has been used so widely because of its conceptual flexibility. It allows experiences as distinct as pain, shame, and financial insecurity to be considered within the same episteme, described in relatable language, and weighed against one another when an action is to be taken. Furthermore, it foregrounds the complex connections between different forms of suffering. This is the concept at the centre of the ethnographies below.

Ultimately, it is useful rather than confusing to combine together different categories of events, because it is the totality of these experiences that constitute the narratives of illness. The biographical portraits that follow, then, are an attempt to see how the different forms of suffering detailed above arise in different circumstances, but also how they spill across these categories through the complexities of daily lives.

Ethnographic case studies

As discussed in the Chapter Two, I first experimented with focus groups in an attempt to draw out distinctive themes and overarching similarities visible across individuals in this setting. I suspected, however, that the rote answers I was given in these settings signified that the KAPOP members were neither inspired nor impressed by an attempt to distil their lives into a single, digestible message. Indeed, it felt uncomfortably close to the kinds of stereotypes and simplifications that were already projected onto them all too often.

 A more ethnographic, individual approach was required. In particular, the understandings of suffering that drive this chapter suggest both the need to listen to the rarely articulated, and the need to understand the temporal nature of suffering. That is to say, both in a longitudinal sense – and I was lucky to know some of the people in this study for many years – and in a sense of listening to their life stories, and understanding how they thought about the future.

Nafisa

Nafisa experienced perhaps the most serious and sustained suffering of any HIV positive person that I had spoken to. In her mid-40s, she lived close to the KAPOP office, and consequently spent a lot of time there during the day. A widow with no children, she also had no regular employment. When I volunteered for KAPOP, she would often already be at the office when I arrived in the morning, and was still there when I left at the end of the day. Aside from occasionally sweeping the floor, she rarely contributed to

KAPOP's projects. Nafisa got on well enough with the other KAPOP members, but no one sought her opinions or help, and she did not offer them.

When I returned to the office several years later, it seemed little had changed. Nafisa was still at the office almost every day, and still a neutral, continuous presence. She would often talk about a new business venture she was planning. Wry smiles from other members indicated that they expected little from these schemes – and indeed, they did seem to be perpetually in the offing, rather than actually taking place. For many KAPOP members building a livelihood (particularly for widows) was a key task (which is discussed at length in Chapter Six). Like many, Nafisa tried various kinds of petty trading, but seldom for very long. She would fill a cool box with soft drinks and sell them by the road for a few days – but the next week the cool box she loaned from KAPOP would be sat back in the office, upturned and unused. Other similar ventures also came to little.

KAPOP members mentioned, with moderate scorn, this inability to stick at something. "Well, she's always complaining about not having any money, but it's the same for all of us", one mentioned, capturing a broader sentiment. Those same members said that this had not always been the case – in the years before my first visit, she apparently used to be far more active within KAPOP. I gave little thought to the cause of Nafisa's apparent malaise until much later, towards the end of our fieldwork when we began to talk more. She spoke little about the future, rarely mentioning either anxieties or plans, nor did she spend much time talking about her past. She did however talk about her daily life at length, and offered an unusual perspective of the boredom, repetition, and marginality in the life of the stigmatised poor.

Sometime in 2010, Nafisa stopped coming to the office regularly, presumably because of a problem with her leg that made it painful for her to move about. Despite encouragement from myself and others, she refused to seek treatment. She would also complain frequently about headaches and her

various skin problems. I tried to argue that it was likely that at least some of her maladies could be treated quite easily – why suffer unnecessary pain?

> *"The thing about HIV is that it cannot be removed. I have had a change that is permanent. There is nothing I can do now. I have seen some of those people at KAPOP, even ones that were fine, suddenly become feverish and die – that will happen to all of us one day."*

This sort of morbid talk was her leitmotif, and understandably frustrated many KAPOP members. The ARV era was extending lives and limiting pain, but Nafisa seemed to think that these benefits could not reach her, or perhaps that she did not deserve them. "I have talked with so many doctors, right from the start – what good is talking?". The futility of discussing problems featured frequently in conversation. "At the meeting[44] they asked us to say how does paining leg feel, how does paining skin feel – we all know how it is, but that does not stop it".

Around the time her leg injury began to restrict her mobility, she also became less active. When I would visit for lunch, she appeared to have only recently woken, additionally she seemed progressively more lethargic, ate little, and did not linger in conversation with her acquaintances as she used to. I am not competent to assess her medically, but she appeared to present many common symptoms of clinical depression. When Maryam (another KAPOP member discussed below) and I lunched with Nafisa, Maryam suggested to her that she should "be more active and become more visible at the stall". Nafisa used to help out, or at least participate in a roadside fruit and vegetable stall that a group of women, several of which were KAPOP members, managed. But she had ceased to visit the stall.

Others offered similar advice – to get back into regular routines and engage with a wider circle of people – which seemed to be both well intentioned and

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[44] This referred to a meeting the previous week with two visiting nurses who asked a group of assembled KAPOP members to rank what they thought the most common HIV-related symptoms were.

sensible, regardless of whether she was clinically depressed. Nafisa would deflect such encouragements, with alternating playfulness and irritation. "You know how I am with my leg, I am an old woman now!" she protested to Maryam. When Maryam explained that a friend was visiting the stall by car, and could collect Nafisa as well, her reasoning shifted "well, I'm feeling very down, I don't want to be outside".

This pattern repeated itself – Nafisa never withdrew completely from KAPOP, and was always friendly enough to make sure visitors returned. But she also consistently resisted attempts at intervention by pointing to a vague combination of physical, psychological, and social pathologies. A suggested treatment for her ailing leg saw her deflect by referring to stigma that would take place at the hospital, whilst attempts to ameliorate her deteriorating mental health were rejected because her physical pain was too severe.

In the interview where I was taking notes, I was sufficiently frustrated to ask her directly 'what exactly do you think is wrong with you? It seems like there is always something, but it's often different every time?' Her reply placed the blame on outside world: "Everything is changing, and Kebbi is becoming a very difficult place. It is so dirty, so dusty, and the people are becoming a big problem". Some of these criticisms were widely voiced amongst Birnin Kebbi's residents – indeed the city has for sometime been transforming from a regional town to medium-sized city, with change in population density and pace of life that that implies.

Nonetheless, the vehemence and frequency with which she expressed these views, and way in which they were a catch-all reason for staying in her small home suggest something profound. Through some difficult-to-differentiate nexus of social, psychological, and physical suffering, the world that Nafisa used to move through with relative confidence has become a far less appealing place. Her reluctance could be read in medical terms, some

agoraphobia[45]-like syndrome perhaps. But to do so would risk being part of the process of dehumanisation – to reduce her lived experience to a pathology.

Turner explains that "serious illness, along with grief and other extreme experiences, provokes a shift in the embodied experience of the lifeworld, leading to what literary theorist Elaine Scarry (1985) calls 'the unmaking of the world'" (2005:118). Or simply, the normal and the everyday takes on an unfamiliar, disquieting quality:

> *"When you see them pushing and shouting at the market or the motorpark, you think, really? Are we now treating human beings like cattle? But it is the same with all this in Iraq and Afghanistan – killing and bombs, and what is the reason for all of this?"*

Nafisa often watched Al-Jazeera on the KAPOPs free satellite television, and also regularly listened to the news on the radio. When we spoke, she often wove violent events from afar into her own idiosyncratic laments at a world in decline. Her suffering – acute, but obscure in its exact aetiology – was experienced as dehumanisation, but not of a vilified individual or group, as Hannah Arendt (2004) describes. Instead, Nafisa's suffering was a perceived dehumanising of the world.

Life with HIV for Nafisa meant a city that was ever more inhospitable, filled with long, uneven roads that must be walked and unthinking crowds that cared little for her senses that had been heightened through isolation. It also meant acquaintances bristling with ready-made instructional tips, but without the time to unpick Nafisa's indistinct maladies, and learn how her world had closed in on her. Her own suffering included absorbing, incorporating and observing other characteristics in those around her – particularly with KAPOP – perpetuating and expanding the scope of her

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[45] Agoraphobia has indeed associated with HIV in various contexts (Els *et al,* 1999; Spies *et al*, 2009).

social suffering. Despite their willingness to offer advice in the short term, ultimately, no one seemed to know what could be done to help her.   Like João Biehl's subject Catarina, Nafisa had slipped into a "vacuum of policy' (Biehl, 2005: 84), a place where neither formal authorities nor informal networks of support could reach.

Hadiza

Whilst Nafisa shared the alienated dislocation of Biehl's Catarina, Hadiza, another KAPOP member mirrored Catarina's misery in a different way. A key aspect of Catarina's decline was her relationship with her family. The trajectories of Catarina's various family ties – especially with her ex-husband and in-laws – are too numerous and complicated to fully recount. To summarise, Biehl argues that the family, when faced with Catarina's costly and embarrassing psychological instability, chose to collaborate with medical authorities to secure her safe marginality. Thus, instead of acting as a compassionate counterpoint to impersonal formal authorities, families can "work quite efficiently alongside established institutions in generating new forms of institution that drown out the person and ultimately determining the course of his or her life" (*ibid.:*145).

For Biehl, when faced with tough choices a family can be callous: "They invent thousands of excuses to get rid of the problem. If they do this in the family, what about a person they don't know?" (*ibid.:*262), can redirect medical resources according to their priorities, such as a "psychiatrist [who] is not for the patient, he works for the family" (*ibid.:*252), and most damningly, can take on the damaging logic of state abandonment, acting as "the medical agent of the state" (*ibid.:*22), ruthlessly triaging care, deserting individuals who "were not left to die simply because they tarnished the family's social status; worse, they occupied space and consumed an important portion of the family's goods and attention." (*ibid:*142).

So things largely had gone for Hadiza. She described her background as from a humble but respectable Muslim family who ran a small shop and farmed a modest plot of land in a town in Kebbi state. She married at 15, and

when I first got to know her in 2006, she was in her early 20s, with two infant children.

Of all the 'disclosure stories' I heard, Hadiza's was probably the most severe. Discovered during a routine maternal screening during her second pregnancy, her family and husband were apparently told of her status before she was (or at least before she properly understood). She describes how she was publically blamed for bringing shame onto her family, her husband's family, and her husband himself, and was beaten.

A chance recommendation from a staff member at the clinic in the town where she lived put her in touch with another HIV positive woman known for giving advice and support, and she in turn put her in touch with KAPOP. Hadiza was vague about whether she was explicitly cast out or simply ran away, but either way when she came to Birnin Kebbi (her first visit to the city around the age of 20) it was made plain to her that she was no longer welcome at her childhood home.

At first Hadiza stayed briefly with family friends of the KAPOP chairman, and later in a small shared flat with two other KAPOP members.   When I first met Hadiza, her two flatmates had left (in one case, to live with a new husband and in another to stay with relatives outside Kebbi), and two new flatmates had moved in. For many in KAPOP and for Hadiza herself, this served as both evidence of and a metaphor for her stagnation. The flat[46] was intended as a short-to-medium term refuge (perhaps for three to six months) for HIV positive people with nowhere else to go. It was understood to be only available to women, presumed to be those thrown out of their previous homes.

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[46] The flat was not owned by KAPOP, nor did they pay any rent for it (though they did cover various maintenance costs such as replacing a broken window and new light fittings on an intermittent basis). How it came to be under their control was somewhat obscure even to the KAPOP membership – it seemed to be a legacy arrangement made by the previous coordinator that had continued.

Clearly, Hadiza's multi-year stay went beyond the flat's ostensive purposes as a site for temporary rehabilitation. Her medical progress, also, was a source of disappointment and indeed scolding from KAPOP members. She was said to be careless in taking her medication, taking the pills in the wrong combinations, or forgetting to take them at all. She admitted as much "of course I know that taking them correctly is important, but some days I feel quite sick"[47]. Common side effects of ARVs, which can include nausea, are often a barrier to drug adherence (e.g. Reynolds, 2003; Molassiotis *et al,* 2002 and Johnson *et al,* 2005).

On other occasions, however, Hadiza's responses were inconsistent and vague. Sometimes she would say that she simply forgot, yet her flatmates told me that they were assiduous in reminding one another about their regimens (which were identical), even going so far as to set matching alarms on their mobile phones, which would sometimes chirp together as I visited. Other times she would say she had forgotten to pick up her drugs, yet the coordinator of KAPOP said he always made sure she was resupplied (in any case, he pointed out, she could borrow from her flatmates if she ran out).

This mystery was partially unwound when I asked a different question; about whether she had been able to rekindle relationships with any of her extended family:

> *"I'm not really with them, but every time I take those pills I remember what I am. What I am is the reason that I am stuck here. And the pills come every day, so I will never forget that I can't go back to my village."[48]*

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[47] *"Gaskiya na san cewar shan magani kan lokaci kamar yadda ya kamata yana da matukar muhimmanci, amma gaskiya wani lokacin nakan samu kai na a cikin halin rashin lafiya sosai wanda yakan hana ni yin hakan"*

[48] 'Village' used here in the figurative sense of 'home town'. *"Ban cika tunanin ina dauke da wannan cutar ta HIV ba sai idan na zo shan magani sannan yake zuwa mini a rai na. Wannan shine kawai abin da ya tsaya min a yanzu saboda kullum ake shan maganin, saboda haka ina tsammanin ba zan taba koma wa kauyen mu ba a cikin wannan halin."*

For Hadiza, then, the drugs served as a reminder of her isolation and shame. Unfortunately, the dynamics within KAPOP did not reduce this association, but instead tended to deepen it. This demonstrates, then, the social entanglements that can make adherence more difficult.

Hadiza was a well-liked KAPOP member, helpful at events and always available to run miscellaneous errands. Yet her long-standing tenancy at the flat, and her frequent relapses and associated poor drug adherence meant that she was seen as a dependent more than a provider. Sadly, her availability and visibility combined with her dependence on KAPOP, tended to mean that she was used as a prop or case study for both internal and external audiences.

One example came when two nurses visited KAPOP from the Muslim Nurses and Midwives Association of Nigeria. They had been conducting training workshops for nurses in Birnin Kebbi, and were visiting KAPOP for what was billed as a 'courtesy visit', but which turned into an impromptu lecture or training session for 20-25 hastily gathered KAPOP members on the importance of nutrition, hygiene and drug adherence for HIV positive people. When the nurses said that they had heard cases where poor drug adherence had led to secondary infections, a male KAPOP member pointed in Hadiza's direction and said 'Yes, that's definitely true![49]'. The KAPOP coordinator intervened, I hoped to preserve Hadiza from further embarrassment, but to my horror mentioned her by name: "Our sister Hadiza has had this problem, and got quite sick last year".

I was shocked[50] by this public act of shaming, and afterwards asked the KAPOP coordinator – usually sensitive to issues of confidentiality why he had mentioned her by name: "It is important for our members to know that this adherence is a serious thing, you can't play with it."

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[49] *"Wallahi! Gaskyia ne!"*
[50] The notebook I used for that day has ink stains, as I bit the top of my biro open in frustration as I willed myself not to intervene.

On another occasion, when a state Ministry of Health official visited, this time just with two KAPOP officers and three ordinary members including Hadiza (who was there coincidentally) present. Again, Hadiza was used as example of how things could go wrong, this time to make the case that more support from the government was needed. As Hadiza sat with her eyes cast to the floor, sullen and submissive, the coordinator told a highly stylised version of her life story. The facts of her being forced to leave her home and her town were accurate, but the coordinator argued that that she had been unable to take her drugs properly because she was not able to get to the hospital to collect them, and that she didn't have enough food to take them with.

Neither of these things was entirely true: as discussed above, Hadiza's adherence problems were more psychological and complicated. But in this context, she was a convenient stand-in for the archetypal pathetic, abandoned widow. Aside from the barely audible mutters of assent, she literally had no voice in this performance, as mute as a starving child photographed for a 1980s famine appeal. Her own reasons for not taking drugs were irrelevant, and her dependency on KAPOP gave her little choice but to consent to this process of institutional self-presentation.

As unedifying as these events (and others like them) were, the point is not to castigate KAPOP and its officers for their insensitivity. After all, as discussed in the introduction, they are an organisation of only partly trained non-specialists asked to deal with extremely difficult and complex tasks, balancing the care for their members with the search for new resources. They mostly operate in an unpredictable and often unhelpful social and economic climate through improvisation.

Hadiza's case, however, highlights the limitations that such patient support groups are likely to face. KAPOP was often able to offer a certain level of material sustenance in desperate cases, and could provide a general form of emotional support. In more complex cases like Hadiza's, where social suffering and past trauma were being fed back – through a lack of self-care -

into worsening health problems, KAPOP was decidedly out of its depth. At worst, like Hadiza's family (and like Catarina's family in Biehl), a support group can start to function oppressively, sucking what little self-esteem remains from people, unable to tackle serious problems. Suffering for Hadiza, then, is in part about her being stripped – whether intentionally or not – of responsibility and autonomy over her care.

The officers of KAPOP had neither the time nor the expertise to come to terms with Hadiza's opaque reasoning and mental state (which, as with Nafisa, may well have involved undiagnosed depression). Instead, all they could do was to simplify her story into a more comprehensible and actionable trope – that of the helpless widow.

Similarly, a façade of compassion[51] in a support group conceals complex political imperatives and relationships. The support KAPOP offered could easily become unhelpful dependency. It is often suggested that support groups can do the social, psychological side of care that the material and biomedical focused state is ill-equipped to provide (Davison, Pennebaker, and Dickerson, 2000). This example suggests that this capacity may be overstated. Instead, KAPOP tends to be trying to pick the same 'low hanging fruit' as the local hospital. Complex suffering that defies conventional narratives will continue to be a difficult target for institutional responses.

Hadiza's experience suggests a social role for the suffering body in the anti retroviral era, as an example, and a symbol. It reveals the kind of selection logic that even sympathetic organisations deploy – that is, to act as cautionary tales, to illustrate best practice and reinforce compliance by singling out those who are not responsible enough to effectively alleviate their own suffering. Organisations responsible for improving lives can, cruelly, depend on maintaining – or at least showcasing – examples of suffering.

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[51] I do not mean to imply that KAPOP's compassion is wholly fraudulent – merely that there is a (perhaps) inevitable disconnected between the group's public account of its work, and the more complex, uneven reality.

Murtala

Murtala, a school teacher around the age of forty, was one of the last HIV positive people I spoke to during my fieldwork. He was not part of KAPOP, though he had heard of them, and was acquainted with several members. We had been introduced by a friend in 2009 (our mutual acquaintance was a doctor, though Murtala was not one his patients). As we were introduced, our doctor friend told me that Murtala 'would be interested in the subject of my research', which I took to mean that Murtala was HIV positive. However, Murtala did not seem interested in pursuing the conversation, and the connection lapsed.

I barely saw Murtala for two years, until we happened to attend the same wedding, and he asked for my number. Later the same day, he called and asked to visit, saying he wanted to talk about my work. When he visited, he said he was impressed that my Hausa had improved[52] and that he said he thought my research – from the précis I gave him at the wedding – was interesting and important. He said that he had a lot of relevant things to say, and repeatedly used a variation of the phrase 'there are things that your people need to learn about HIV', with 'your people' referring, it seems, to the Western policymakers and researchers that he took to be driving HIV interventions.

He became a semi-regular visitor, often stopping by unexpectedly. He usually needed no encouragement to talk, arriving bristling with topics to share with me. His themes ranged from the commonplace (e.g. how HIV could be stopped with a more moral society, with married men behaving more faithfully), to the political (how Western economic domination was a form of neo-colonialism, leading him to be suspicious of international health development programmes), to the idiosyncratic (various conspiracy theories,

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[52] Ironically, now that I had demonstrated some competence in Hausa, he tended to speak to me in English – one of many occasions when my language skills were at least as useful as a badge of commitment as for communication.

involving politicians he suspected were trying to cure their HIV through sex with virgins and children).

I asked why he had chosen not to get involved in KAPOP, and why he didn't use the scheme at the state hospital; Murtala was registered as a patient at Usman Danfodiyo Teaching Hospital in Sokoto, and travelled there once every two months to collect his ARVs. He explained that his view of HIV doctors and HIV NGOs had been soured by experiences in Kano, where he had lived until 2007. After diagnosis, he was referred to a support group, and indeed became an active member for a time, assisting in project work. He said KAPOP reminded him of that support group: there were well-meaning people, but trapped in logic of the NGO sector: *'kasuwa ne'* he often said – 'it's just business'. He was also disturbed by patients theatrically seeking treatment, particularly at meetings with authorities, telling their stories in what he thought was a florid and undignified manner:

> *Whenever there is a meeting [with a visitor] everyone is crying, sobbing and saying they are an orphan and their children are starving and so on and so on. And you know, some of them are driving new cars, and are even schooling their children in the US or somewhere. It is not an honest business[53].*

Did he feel that now he did not require the kind of support that either KAPOP or doctors had to offer?:

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[53] Whereas most of the previously cited discussions took place in English, in this and subsequent sections, I quote conversations that took place in Hausa. I provide the original text, clarified by an assistant, below: *"Duk lokacin da muke taro zaka ji kowa yana korafin cewa yayansa marayu ne kuma basu da abinci saboda haka suna da bukatar taimako da sauransu, amma ka gane, yawancin Yayan su suna shiga manyan motoci sannan kuma suna karatu ne a kasashen waje kamar su Amurka da sauransu, saboda haka ina ganin wannan sana'a babu adalci cikin ta"*.

This business of getting counselling or a sewing machine, that is not my
problem. You know me, my problem is that I am always arguing!
Sometimes I am shouting at you about Tony Blair or whatever![54] [laughter]

It was true: he was a moody character, and his political rants about the West
sometimes had a personal edge. But he was not without good humour. He
was sufficiently self-aware to recognise that he had become grumpier over
time as weight loss and muscular pains had nagged away at him.

Before this [HIV] I was not really the like this – I was quite relaxed. But how
can I relax now? I am so thin, and sometimes I ache for no reason.[55]

But these were not his primary source of anxiety. Unlike many, he had been
able to preserve his family life. He lived with his wife, and his three children
were all studying.

What will happen to all of them if I get very sick? What will happen when
the [hospital] bills become tens of thousands of Naira?[56]

Like Maryam (below), his biggest fears were for the future, that he would fail
as a provider, and become a liability. This was how things were for HIV
people now:

Before, you could go quietly, and all these problems you have about stigma
mean nothing. You are in Allah's hands. But now there is no escape[57].

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[54] *"Samun shawarwari daga gare ku ko kuma Keken dinki da kuke bayarwa ba su ne*
matsala ta ba yanzu ! Abun da ya fi damu na shine yawan musu, wani lokacin nakan dame
ka akan Tony Blair ko wani abu kamar haka."
[55] *"Kafin na kamu da wannan cutar ai ba haka nake ba, da ina cikin kwanciyar hankali,*
amma yanzu ba hutu, sannan kuma duk na rame, wani lokaci sai na yi ta soshen soshen da
babu dalili."

[56] *"Me zai faru da su gaba daya idan rashin lafiyan nan tawa ta tsananta? Sannan kuma*
idan kudin asibiti da kuma na magani sun kai dubunnan Nairori?"
[57] *"A da can zaka iya mutuwa cikin cirri ba tare da wata tsangwama ko kyama ba. Rai yana*
hannun Mahaliccin mu Allah, amma a yanzu babu wata mafita."

Notwithstanding the issue of whether untreated HIV constitutes 'going quietly' (such deaths are often agonising), Murtala articulates a significant pivot in the HIV experience. In the pre-ARV era, the possible trajectories for the HIV positive could vary somewhat, but ultimately largely followed a predictable arc of wellness, followed by repeated illness, and then death. Now, despite being obviously a net positive, the ARV era has opened up all kinds of possibilities, but also all kinds of challenges and often different kinds of suffering.

The centrality of economics and his responsibility as a provider to Murtala's suffering and anxiety suggest a story more like the ones often told about HIV in Africa – of generational and economic disruption, of families taking on scarcely manageable burdens.   For Murtala, perhaps the most potent symbol of this anxiety was his car, a stately, early 1990s Mercedes Benz saloon that he had bought from an uncle many years ago. He liked that it was distinctive, neither gaudy like a new Land Cruiser, nor quotidian like a Corolla. Like for so many, Murtala's car conferred mobility freedom (Hay and Packer, 2003; Urry, 2004).

But it was expensive to maintain, and took an increasing part of his salary to keep on the road, and it was too old to be worth selling for something more reliable.

> *I used to check everything very carefully, every Saturday morning and do almost every [repair] work myself. But the virus has just hit me, and made me weak, and I just rest. I know sometimes, especially when it is hot, it will be finished. At that time, how will I visit my people, and go to the market to pick my wife? There is no pill for that problem.*

Maryam

Maryam was widely regarded as an exemplar of a 'successful HIV positive person'. In her mid-20s when we first met in 2006, she was both beautiful and charismatic – when a photo of KAPOP members was required for a

donor organisation, everyone knew Maryam had to be at the front. She was one of the first people to meet me when I moved to Birnin Kebbi: 'Mr Peter!', she would bellow across the living room area where KAPOP members met, 'are you here to do something useful at all? Why don't you sit with Zainab and help her cook stew for us!'. Always teasing, with an attention grabbing joke and a flirt, she was by far the most confident of the women in KAPOP. In time, however, it became clear that she was a more complex personality, as likely to be muted and shy as raucously outspoken.

Often this boisterousness was manifest in group meetings – forceful and articulate in making her points – again, more assertively than almost all the other women, despite her youth. Yet in those same meetings, and in conversation in small groups, she could also be unexpectedly abrupt and reticent – quickly becoming bored with a line of discussion she had opened, or starting to make the case for how a task could be divided up, and then refusing to elaborate.

Her vivacity was also coupled with great competence in doing various administrative and logistical tasks for the group, which more than compensated for her morose periods. When myself or the organisation's chief executive needed a funding proposal countersigned by an official at short notice, or a missing sewing machine needed to be tracked down, at least as often as not, we called Maryam. Nevertheless, I was intrigued by her often-incongruous behaviour.

Over time, in numerous conversations with herself and her friends, a version of her life history emerged. Maryam came from a prosperous background. Her mother was a head teacher in her home state down in South West Nigeria, and her late father had been a civil servant. She had moved to Birnin Kebbi after the completion of her studies as part of a year's national service. All Nigerian university graduates are required to serve for one year in the National Youth Service Corps (NYSC). The scheme was established in 1973, in the aftermath of the Nigerian Civil War in Biafra, "in order to…'raise the moral tone' of Nigerian youths, to make them 'more amenable to

mobilisation in the national interest', inculcate a sense of patriotism and promote a sense of national duty" (Obadare, 2010:1; see also Marenin, 1979). Those serving on NYSC programmes typically undertake public works, either of a general nature, or connected to the profession for which they have studied – for instance, work in HIV prevention education (Omorodion, *et al,* 2012).

It is a significant programme for this study in two ways. Firstly, especially for rural (and somewhat unfashionable) states like Kebbi, the NYSC scheme is an important opportunity to supplement medical services with newly qualified staff who might otherwise not visit, both during the year of service, and potentially longer if incentives can be found to retain them (Awofeso, 2010). Secondly, it is a major driver of mobility and inter-cultural exchange within Nigeria, both for the graduates themselves and (particularly if when corpers stay on after their service) various family members and dependents that may decide to join them. Despite concerns that the scheme is under-funded and often poorly administrated, it nonetheless remains an important means of facilitating interaction between Nigeria's various regions and linguistic groups.

Like many 'corpers', Maryam had never visited Kebbi before (indeed, many had never visited anywhere in the North). She spoke little Hausa at first, but quickly gained a working fluency, and shortly after the conclusion of her service, she took up a secretarial job at a Federal Government agency in Birnin Kebbi. She quickly developed other ties to the region – her sister from her home state moved to stay with her, and she got married.

Maryam rarely talked about her marriage. I learnt from others that her husband was a businessman who stayed in Sokoto (some 2 hours drive away) but travelled frequently to Birnin Kebbi. Such third-party accounts after the fact are hard to verify, but it was suggested that he was handsome, charming, disloyal and promiscuous. Everyone presumed that it was Maryam's husband that had introduced HIV into their marriage.

However, he reportedly blamed her when she fell ill, and left her. It was an occasional topic of conversation amongst colleagues, and was generally characterised as a particularly unpleasant and perhaps abusive split. It had also clearly seriously weakened her ties with her extended family back home, with visits back home becoming very rare.

Maryam, therefore, found herself in a somewhat unusual position. Young, single, divorced (at least in a 'de facto' sense), HIV-positive, with a largely dependent sister, without other family for support. Yet also, she was professionally successful, progressing unusually rapidly within her workplace. We spoke a good deal about how she saw herself, and how her illness and experience of suffering had affected her:

> *It all happened between two Christmases. One year, I travelled with [my husband] back home, and we stayed with an uncle, and it was very nice. We were very popular, and they wanted to know when I would be expecting [a child]. But early that year, I got a fever and was told I had the virus. My husband knew, and it became very bad.*

She never discussed how her husband found out, or who told her family (who also discovered her illness in short order). The consequences were devastating however, as her husband left and stopped paying for the small one-bedroom home that she shared with her sister, and her family refused to help her with a deposit towards a new rental[58].

> *And then when it got really hot, I had these marks [facial scarring from a (presumably HIV-related) skin complaint] for the first time. I was really embarrassed to have people see them and talk.*

Maryam felt that her skin marks were the tell-tale sign of her HIV status – or at least they were in combination with gossip about her marriage. This

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[58] A systematic review (Leaver, 2007) suggests that housing security is a strong predictor of wellbeing for HIV positive people.

completed a devastating triumvirate of social shaming – from her husband, her family, and those she knew at work and church, who put the clues together.

> *"You know, I really thought things could not get any worse. I had this fatal disease, and everything was collapsing. Only [my sister] was still here. And my job, that was one thing that was still there. So I decided I would do everything in my power with that."*

Unlike some of the other individuals mentioned who experienced a prolonged series of calamities, Maryam's crises all happened at once. Aside from the skin complaints and the bout of fever that led to her HIV test in the first place, she was not otherwise unusually ill in that year:

> *You know we Nigerians are a very sickly people, always getting malaria, and this and this and so on, but actually that year I was feeling very strong. But all the things I was planning were lost.*

Maryam's primary anxieties became about her career, her responsibilities towards her sister, and her social standing. With little immediate physical pain, her suffering was largely experienced in what was to come. It was a suffering of lost potential, and intensified fears for a future she could not control:

> *I can tell you, in those days, I was seriously worried almost everyday. How can I go on when I cannot move home, but everyone here [in Birnin Kebbi] knows about me? How will I support [my sister]? Who will look after me when I am sick?*

In time, Maryam said that she began to come to terms with what happened. She began to see it less as a unique and horrifying experience, and more as one of many bad things that can happen in life. "We all live in God's time" she often said, and compared her own fortune to those killed in Kebbi's frequent road accidents.

When I was less shocked, my real pain was thinking about what I had to do with my life. I knew I needed to become an independent woman. So I made sure I worked very hard and was always reliable.

Knowing of Maryam's competence within KAPOP, it is easy to understand her rapid progression at work: "And actually when I began to give one hundred per cent [at work], I realised I was my own boss in this life." Furthermore, Maryam felt that her skin problems paradoxically made people treat her more seriously at work, and unwanted sexual advances from her male colleagues dried up: "It was very strange – one day I was a young African woman and they were African men, and I think you know that situation. But after [her status became widely known] people didn't know how to treat me – but there was not really discrimination, I just became a worker." On several occasions, Maryam joked that she had become an 'auntie' (i.e. respected elder) at work, in spite of her youth. Within a year, she had been promoted, a marked contrast to the "downward spiral marked by fatalism, self-loathing, and isolation from others" (Rankin *et al*, 2008:703) that often accompanies HIV stigma.

Nonetheless, Maryam clearly still experienced intense suffering of a different sort. "Since the virus, I know that things can be taken from me. I have been quite strong [i.e. healthy] for years now, but I know from the others [at KAPOP] that things can change. Will these medicines keep coming? I don't know". Other studies have shown that the anxiety of patients increased when they knew others with the same diagnosis that had died (Öhman et al, 2003:535), and that a death within KAPOP triggered deeply felt fears for the future. Therefore, the uncertainty over the future supply of treatment itself became a form of suffering.

It is a little trite to say that Maryam's swings between confidence and sullenness reflected her mixed experiences with HIV. Nonetheless, she is an example of a particular kind of social suffering, in which the burden of pain is neither loaded primarily onto the body, nor experienced as the immediate

burn of social humiliation (though to be sure Maryam experienced some of the latter). Rather, the most severe suffering is that of a greatly increased precariousness of welfare or livelihood, and a constant awareness that successes gained in a post-HIV life can easily be undone by a capricious supervisor at work, or a downturn in health. Thus such personal victories are both a source of great satisfaction, but also intense anxiety.

Summary

The case studies above demonstrate the varied and multifaceted nature of suffering in the ARV era. They suggest that suffering has many different causes, and that people respond to it in different ways. They also defy simplistic assumptions about what family or support groups can do.

Some, like Nafisa, find that suffering isolates them, and the isolation itself becomes a form of suffering. In such cases, it seems the city – perhaps the world itself – is experienced as a source of suffering, particularly as ailments reduce mobility. For others, such as Hadiza, suffering is intensified and maintained as a consequence of organisational logic. The support group, however well intentioned, came to see her suffering as expected and required, even useful. All four of these individuals worried about the future. More than most, Maryam was able to use her experience of suffering as a spur of encouragement towards a new and more promising life course. But even for her, burdens of responsibility and fears for the future meant that her life with HIV was experienced as something quite different from a cheerful, straightforward success story.

For each, minor-to-moderate health problems – often skin complaints – niggled away, both a constant reminder of their status, and sometimes as public disease markers. The question of mental wellbeing hangs over a great many HIV positive people. For some, it is obvious and clearly visible. For others, the suffering experienced and the suffering yet-to-come was indexed temporally into past suffering and suffering yet to come: the uncertainty of the health, their social status, and future supply of medication understandably weighed heavily, as did past trauma.

People dealing with HIV have multiple experiences, with different overlapping and interacting sources of suffering. In the pre-ARV era, however, the predominant focus of both HIV-positive and their caregivers was focused on alleviating bodily pain, even as many other forms of suffering were present below the surface. Abbreviated lives meant that these different kinds of suffering played themselves out quickly, and social suffering was noted by scholars more in the absence of the suffering body, the consequence of the disease running its course. This is visible in the voluminous literature on the consequences for children in the absence of a parent or breadwinner (Foster, 2000; Bicego, Rustein, and Johnson, 2003; Cluver & Gardner, 2006) and social institutions of all kinds, as many of their most productive members are 'hollowed out' (e.g. De Waal, 2003, Seckinelgin, Bigirumwami, and Morris, 2010).

Thus, these case studies explore a new era, as policy interventions combine with changing livelihoods and places to produce and modify new kinds of suffering. With increased survival rates and longer lives, both the material suffering of the body and the forms of social suffering have shifted. This is nominally represented in some of the groups like KAPOP – which exists to provide support for those still living. But they operate only in a limited manner, through supporting the individual: organisations like KAPOP can do little but attempt to repair damage wrought by social and familial rejection. Indeed, at times, as in the case of Hadiza, it risks rebroadcasting those same logics of shame and stigma. It is, as Pullman argues:

> *"Self-constituting projects are often frustrated by disease. Pain can rob persons of the physical capacity to pursue meaning conferring endeavours. But suffering can also be the product of psycho-social, economic, or other factors that frustrate an individual in the pursuit of significant life projects."* (2002, 83).

Furthermore, the burden for alleviating social suffering is still cast upon the suffering individual. This brings with it a responsibility to comply, and

expectations to make the best of things, and ultimately to create a space for *living* with HIV rather than merely *suffering* with it. This leaves unaddressed the relationships that are created by, with, and in exclusion of, suffering people.

These insights have various implications. It is clear that interventions to support treatment and care must recognise what complex phenomena stigma, shame and self-loathing can be. They must also recognise how psychological suffering – whether or not it is formally categorised as a 'mental health issue' – is similarly potent. Fears about the future and trauma from the past often deeply trouble even those who appear to be 'model patients' who are 'coping well'.

Finally, the research process itself was revealing in that so many were willing to talk about intimate aspects of their lives. This is only in part a reflection on the longstanding relationship I had with some. It also suggests that the acts of talking, unburdening, and being witnessed themselves have power, which complicates the more conventional advice on how researchers should approach difficult topics and vulnerable people.

This project joins a host of other writers who have articulated suffering, either in prose such as Primo Levi (1984) or images, such as Susan Sontag (2004), for the purpose of exposing these complexities. These works aim to make suffering legible though particular aesthetic or intellectual engagements, but always with an eye towards the development and articulation of an ethical framework through which to interpret that suffering (Olson, forthcoming).

Researching suffering, therefore, is both ethically fraught and ethically valuable (as I explore in Chapter Two). Moreover, engaging with and articulating these experiences is central to understanding the ARV era. A fuller understanding of how HIV positive people suffer and how they mitigate that suffering is also a prerequisite to planning better care and support interventions.

Chapter Five - 'The best thing that ever happened to me' – Love after HIV

Introduction

The previous chapter explores how people suffer after contracting HIV, and seeks to expand and engage with existing scholarship on the difficulties of living with HIV. Several individuals exemplified an alternative trend: for them, suffering had the Nietzschean consequence of driving resolve and self-development. These examples are out-numbered, understandably, by those whose lives remain blighted by serious problems caused by HIV. Nonetheless, it is an intriguing trend that finds particularly rich and important expression in another area of post-HIV life.

Attending a small but jovial wedding between two KAPOP members in 2009, I was introduced to a man who was a member of a similar HIV support group in Kano. He had travelled to Kebbi for the wedding. Talking in a group of four or five friends in a sitting room as food and soft drinks were passed around, he turned the discussion to his own remarriage. Amongst friends, he clearly felt he could discuss his HIV status openly. He said he was delighted with his second wife, who he had chosen in part because she was also HIV positive. They were partners in everything and best friends, he said. Realising he had been dominating the conversation for some time, he concluded, shrugged with a smile, and simply said: "well, this virus is the best thing that ever happened to me".

This striking, apparently perverse remark was made all the more memorable by the reaction of the others in the room. I expected laughter; acknowledgement of what I thought was a mordant joke. But instead, the others nodded in assent and agreement. For all the anguish and hurt, clearly many HIV positive people had not merely coped, but found a form of contentment in their lives, and a new relationship seemed to be at the heart of that satisfaction. This chapter explores these relationships.

As discussed in the previous chapter, a HIV disclosure (or death of a partner) will likely often also lead to a rift between an individual's own marriage,
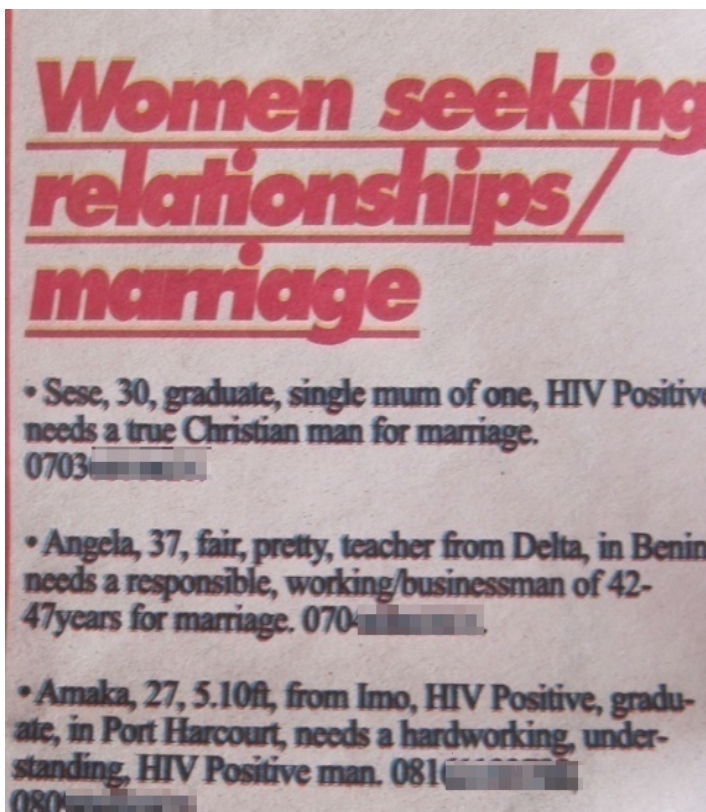
Many personal ads in Nigeria feature HIV positive individuals looking for sero-concordant partners. The Sun, December 10, 2011

extended family, and in-laws (e.g. Porter *et al*, 2004). Friends, employers and even dependents may also decide to dissociate themselves with a HIV positive person. This shunning may come with agonising public scorn and rancour, manifested in discreet withdrawals of support (Rankin *et al*, 2004; Mahajan *et al*, 2008). These distancing moves against HIV positive people can be understood as expressions of fear and stigma, as a refusal to accept reality (for instance, in the case of spouses who do not want to confront their own likely HIV status). Or they may simply be pragmatic steps of self-preservation, taken by nervous family members to protect their own good name.

What is seldom discussed is the double-sided nature of these breaks: the end of a relationship allows for the beginning of a new one, often in a much more carefully considered fashion than in their first marriage. Similarly, damaged or severed family ties bring great practical and emotional costs, but also

presents a means of escape from relatives who are in a position to judge and control.

This chapter hypothesises that the perception of HIV as a positive event can be understood as people moving from a sphere in which their lives are closely regulated by others and their expectations, to one in which they have a good deal more scope in which to consider and pursue what it is they want out of their lives and relationships. This shift also reflects a way of living that aspires to a Western, modern sensibility of intimacy, openness, and reflexivity.

A small but emerging body of literature acknowledges that HIV positive people seek out other HIV positive people to date and ultimately to remarry (Cooper *et al*, 2007; Rhine, 2009; Gombachika *et al*, 2012). Rhine (*ibid.*), also describing a Northern Nigerian context, notes the crucial role that support groups can play as matchmaking organisations for the HIV positive. This function, one surely never anticipated by national and international funders of such support groups, was clearly in evidence at KAPOP – indeed it was a key part of its popularity.

Part of the importance of remarriage is the disreputability of adult singlehood in Northern Nigeria, which as Rhine indicates (*ibid:*378) applies to both Christians and Muslims. Hausa family structures are known for taking varied and adaptable forms (Watts, 1983; Guyer, 1981; Callaway, 1987). However, marriage is a non-negotiable expectation. Importantly, those whose marriages have ended are expected to stay unmarried only temporarily. As Schildkrout explains:

> *"Widowhood among the Hausa is a ritual phase and not a distinct social status. Although details of the ritual waiting period before marriage differ for divorcées and widows, nothing in the formal status distinguishes them: both are single, previously married women eligible for remarriage."* (1986:131).

So it is known that people pursue post-HIV relationships, and it is also known why they do so (at least in broad terms), and what techniques are

used for finding a suitable and HIV positive partner. However, very little has been said about the content and characteristics of these relationships.

This chapter aims to explore the texture and form of these unusual relationships. It elucidates the often-difficult financial and social context under which these relationships must be built, which forces innovation and adaptation. It argues that post-HIV couples can be understood as a particularly modern creation. They are not just modern in the sense that the good health of the partners is made possible by medical technology, but also in the nature of the relationships themselves. Post-HIV couples often describe themselves as being 'modern', and this is indeed an apt description. This chapter documents the reflexivity, the romantic sensibilities, and the new family structures that make these relationships modern.

Literature review and theoretical context

This chapter focuses on a small and rather unusual group of individuals. Nonetheless, this is a subject that illuminates broader issues, as post-HIV couples are uniquely placed to reflect on, renegotiate, or perhaps reaffirm typical relationship patterns.

What is required is a theoretical framing that is sufficiently precise enough to connect with what these individuals and couples are doing to broader cultural processes without smothering their stories. The most prominent topics in the case studies and observations are modernity, love, and improving oneself. Literature is reviewed on each of these topics in order to develop a theoretical approach to interpreting the significance of these topics.

Modernity in Africa

As we shall see, post-HIV couples go to considerable length to distance themselves from their past, and from others. And they often do so in way that explicitly refers to the notion of being more 'modern'. Indeed, some of the features I identify here – reflexivity, romance talk, and new economic aspirations – have been historically connected with notions of modernity.

Post-HIV couples, then, are in the unusual position of being able to experiment with modern forms and ideas, as circumstances force them out of traditional arrangements, and into new ones. I argue, therefore, that there is a significant discontinuity in their new relationships compared to the ones they had before. However, this change cannot be straightforwardly described in terms of what is traditional and what is modern. As Bruno Latour (1993) argued, the notion of pure forms of 'traditional' and 'modern' are, in any case, misleading. Instead, hybrids and blends of ideas and practice are constantly being made and remade.

A related scepticism of the traditional/modern binary can be found in a wide range of Africanist topics, such as the 'inventedness' (or otherwise) of tradition and ethnic groups (famously Ranger, 1983, 1989; but also Spear, 2003; Pels, 1996; and Ooomen, 2005), the extent to which modern ideas are made manifest in unexpected places, be they witchcraft practices (Geschiere, 1997); supposedly 'distant' villages (Piot, 1999) or longstanding chieftaincy arrangements (McCaskie, 2000). Similarly, a whole range of scholarship in development studies explores the problematic consequences of development's close intellectual relationship with modernity (for instance, Knöbl, 2002; Escobar, 1994; and the essays in Arce and Long, 2000).

This diverse range of scholarship shares the principle that labelling a practice as 'traditional' or 'modern' is to invoke mirages that, on approach, dissipate into often convoluted and often contradictory composites. Nonetheless, the terms cannot simply be dropped from this discussion, not least because they are such important concepts for ordinary people, including those in this study. As Meyer and Pels note, "notions of becoming modern continue to wield tremendous power in everyday African life" (2008: 1).

The task, then, is to listen intently to the precise inflections people use when they invoke these concepts or their relatives, and to situate their usage within particular histories. James Ferguson has developed one of the most useful versions of this approach. His sensitive ethnographies pay close attention to how, in Zambia at least, a straightforward, optimistic narrative of development has long since given way to disappointment, uncertain futures

and reinterpreted pasts that are filled with "non-linear trajectories, and multiplicities of pathways" (2008, 9) as well as "loops and reversals" (*ibid*. 14).

A sign encouraging modest dress – at Bayero University, Kano, signed by the 'Dress Code Implementation Committee'

Such paradoxes are easily found in Nigeria, particularly in the more experimental political and cultural period that has followed the return to democracy in 1999.   The Sharia revolution, and a rise in Pentecostal Christianity share much common ground, as Pereira and Ibrahim (2010) point out, in their critiques of immodest dress, sexual licentiousness and homosexuality.

To the extent that such movements are successful, they influence new norms in styles of dress, relationships and popular culture. What was once 'modern' and in vogue starts looking frayed and discredited, while traditional 'backward' ways take on a fashionable new sheen. Such reversals are visible, for example, in the complex politics of Nigerian cinema, where

film-makers are experimenting with self-consciously 'modern' and 'traditional' styles, whilst avoiding the censorship by authorities whose standards are also emergent and under contestation (McCain, 2013).

The post-HIV couples I describe in this chapter, therefore, are navigating and decoding this shifting web of cultural meanings, as with the ideals they aspire to are clouded and complicated by the presence of competing variants. As Brian Larkin argues, a predominant feature of Northern Nigeria is "the coexistence in space and time of multiple economic, religious and cultural flows that are…subsumed within the term 'modernity'" (2002:18).

Such 'multiple modernities', to use Eisenstadt's (2000) formulation, or 'parallel modernities' to use Larkin's (2002), are both a challenge and a resource. These divergent norms, whether heard in the church or the mosque, seen on TV or discussed amongst family must all be processed, tamed and reconciled with one's own life.

The divergent, conflicting ways in which both scholars and ordinary people use the terms 'modern' can cause considerable confusion. Indeed, Benite has argued that, "By multiplying modernities we…run the risk of emptying the term of any concrete meanings" (2011:648; see also, Cooper, 2005). For this study, however, striving to be modern can be defined as striving for a new way of living that is imagined to be more 'advanced' (in whatever sense) than the present or the past.

Ideas about life and romance[59] come from (and are seen to come from) particular places, as well as eras. So overlaid with temporal notions, 'traditional' and 'modern' are geographical imaginaries of 'indigenous' and 'foreign', 'African' and 'Western' and so on. As we shall, many participants had given much thought to 'foreign' notions of love.

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[59] 'Romance' here refers to the notions of the mid-to-late twentieth century – of relationships forged between autonomous, bounded selves (Giddens, 1992; Shumway, 2003) rather than to the Romantic cultural period in the eighteenth and nineteenth centuries.

That changes in marriage and love are seen to have a foreign provenance is in part because of the connection between relationship forms and economic structures. Most prominently, romantic love is underpinned by (or at least intertwined with) a mode of capitalism that benefits from the nuclear family (with its consequent advantages for education and mobility - see Constable, 2009). Thus 'companionate marriage' (Hirsch and Wardlow, 2006) – a relationship of both mutual choice and love – implies economic as well as social changes.

As different connections with global capital imply or enable parallel changes in intimate affairs, romance can be seen as a new hegemony that is, for better or worse, establishing new social scripts and cultural forms – perhaps erasing or subsuming existing ones in the process. One could chart the progress and mechanisms of domination, or emphasise (and perhaps romanticise) various local forms of resistance.

Again, James Ferguson's work, in particular, charts a pertinent alternative approach – one that emphasises local hybridities that selectively synthesise ideas that are perceived as both local and global to meet particular problems. Similarly, the concept of global assemblages (Ong and Collier, 2005) draws attention not to globalised ideas and those that resist them, but to the concrete, specific ways in which global ideas are made manifest in particular places:

> "*As a composite concept, the term "global assemblage" suggests inherent tensions: global implies broadly encompassing, seamless, and mobile; assemblage implies heterogeneous, contingent, unstable, partial, and situated.*" (*ibid.:* 12)

'Global assemblage' seems a rather dry term to describe the emotions, hopes and desires of couples. Nonetheless, it is an insightful lens because it encompasses their ability to draw on highly mobile and pervasive ideas, such as romance as presented in a Hollywood film, and yet refashion it into something peculiarly adapted for their own lives.

They are not adapting wholesale a modern approach to love and marriage – not that such a pristine notion exists anyway – and they are certainly not comprehensively rejecting models that are more common in the region (models which are themselves hybrids formed in different ways over time). Instead, they are a group of people with a particular set of personal, reputational, and financial problems to solve; and as in the process of casting around them, to find the person, the relationship and the lifestyle to get their lives back on track, they find themselves experimenting with new forms of love.

These experiments – sometimes faltering and others fully-fledged – are an exercise in choosing strategically and creatively from a menu of cultural possibilities. The possibilities available and choices made are revealing of the status of post-HIV couples in this region. In many cases they are partly cast out, but also intent on working their way back, back from near-death (at least of a social kind), chastened but liberated – they are outsider-insiders with a highly sensitised understanding of what one must do to succeed in Northern Nigeria. By recording how they see the world, we can view afresh landscapes of love, family and money.

Rethinking money and ambition

One of the most distinctive aspects of post-HIV relationships is that they often take place in reduced financial circumstances. This may be because one or both partners had to leave their previous employment, or move to a new town. The severing of family ties is likely to also have financial repercussions (Whetten et al, 2008), especially given how informal forms of insurance and borrowing typically take place within extended families (Udry, 1990; 1995). Furthermore, as the following chapter explores, HIV treatment itself involves significant costs. Whilst the subsequent chapter deals with the practical strategies people use to improve their circumstances, this section explores how post-HIV couples often adopt a new approach to money, one that emphasises modesty and self-reliance.

Angela had recently married Simon – both Igbo Christians, both HIV positive, and both on their second marriage. I was visiting to bring some

biscuits, and to apologise for missing their wedding several months ago. I knew Angela – though only peripherally – from 2006 when her friend had encouraged her to claim some 'nutritional supplements' (mostly grain and dried beans) from the NGO for which I used to work. Even then, she was 'divorced' (which means a permanent separation, not necessarily legally recognised) from her husband. She never spoke about her previous marriage directly to me, but I understood from others that her ex-husband, a military officer, left her around the time she discovered her HIV status.

Angela was not ashamed of her modest financial circumstances – indeed, she took a certain pride in her down-to-earth sensibility. She would tease me: "See, we live like Bush people here! Can you drink this pure water?" 'Pure water' is the cheapest form of drinking water on sale in Nigeria, usually sold at five naira (around two pence) for a half-litre plastic sachet. An everyday commodity, it lacks the prestige of the far more expensive bottled water that a Nigerian would prefer to serve to an honoured guest. I said it was fine, and joked that maybe I was a 'bush guy' too – crumpled in appearance after a long journey earlier in the day.

She rented two rooms in a five-room house with her husband, and their new baby. "Look at this place" she said, "the walls are falling before they have even finished building the place!" Angela said. It was true, cracks snaked down the walls of the sparsely decorated main room, which doubled as a sitting room and kitchen, with a paraffin stove, pans and crockery stacked neatly in the corner by the back door of the property. These newly-built properties, I learnt, were part of a housing estate in the east of Birnin Kebbi, and were well-known for the poor quality of their construction.

"But even if these walls fall down", Angela said, pausing dramatically, "I will thank God for what He has provided". "See this", she continued, gesturing to the stove, "before I had a gas one with 3 rings, and A/C (air conditioning) in two rooms! But I am so *rich* in my life because I have Simon, and Chinelo" [their infant daughter]. At this point, her husband Simon, swept aside the plastic bead door curtain "Hello Kingsley! Hello my beautiful girls!", he greeted enthusiastically, returning from the shop with

candles. "When they take the light at eight" he said, referring to the semi-scheduled system of power-rationing in Birnin Kebbi, "we must go to your place and on your gen!"

I explained that I didn't have a generator either, though they seemed unconvinced, and continued to apologise for their home and possessions – somewhat down-at-heel curtains, a television which appeared not to work – which they evidently considered to be minor embarrassments. But as we talked about their wedding, how they found a place to rent (often a struggle in the rapidly expanding Birnin Kebbi), and Simon's job as a secondary school teacher, they displayed not only a self-conscious sense of their own modest station, but also a quiet pride that what they had, they had made themselves.

"In the house that is next to this one, my neighbour takes the whole place for himself, and he drives a new car every year. But he is always borrowing money, and his account will be empty just a few days after they pay his salary. That is the habit of the Hausa man." Angela loved to gossip, and loved to talk about money – the bank teller who loved to show off his fancy clothes, but in fact relied on regular donations from his father to supplement his modest income; the pastor's wife who feigned modest circumstances, but was reputedly financing her children's overseas study with church proceeds. And through these stories, a distinctive vision of morality and wealth emerged.

They could be summarised as three broad attitudes:

1) Relying on others – especially extended family members – is not, as widely understood, an inevitable part of life, but a vice and indicative of poor self-control.
2) It is better to live within your modest means, than always be aspiring for greater wealth.
3) Much wealth is ill-gotten, so rich people are likely to be untrustworthy.

I found these attitudes to be very common amongst remarried HIV positive people. Whilst their attitudes differed in emphasis and strength, couples often talked about their financial circumstances in a strikingly explicit way. Almost always, they drew a contrast to their current behaviour and financial situation, with what they used to have and how they used to act before the trauma of HIV.

The trope that Nigerians are excessively materialistic and imprudent in their financial planning is a common talking point amongst all kinds of people, even those who recognise their own failings in this area. But amongst HIV positive remarried people, I saw this coalesce into a particularly forceful critique of avarice, and the embracing of a new financial ethic.

Zainab, another newly remarried lady, and a friend of Angela's, made a similar point:

> *'Before I was always asking [presumably, though she did not say, from her former husband] for things. "Where is my [skin] cream, where is my new dress". Now, I don't have these things, but I am not sad. I thought everyone was throwing me away, and the things I have are things that are mine. There are too many greedy people, money does not give you everything.*

These attitudes can be read in several ways. They could certainly be a pragmatic reaction to the marked deterioration in wealth; putting a brave face on poverty. But with so many couples insisting that they are both poorer and happier, and that they do not miss their wealthier days, I am inclined to take those assertions at face value.

This analysis bears close similarities with scholarship that has analysed the relationship between money and Pentecostal Christianity. Early interest in this topic in the late 1990s documented how churches, in Zimbabwe for instance, often stress the importance of making money. As Maxwell summarises, "if a believer is not accumulating something is wrong with his or her faith" (1998: 364; see also, Maxwell, 2005). Such 'prosperity gospel' churches have often been suspected of operating along self-serving, self-enriching lines (for example, Gifford, 1990; Smith, 2001).

Other scholars, however, have noted that the 'prosperity gospel' can offer both practical and spiritual respite from the economic struggles of urban living. In concrete terms, Hackett argues that "the benefits of the organizational skills they impart and the social networks they offer should not be downplayed. Their progressive, goal-orientated attitudes attract the youth, disillusioned with the empty moral claims of their elders and leaders" (1998:260).

In spiritual terms, the churches can recast personal financial struggles in a more sympathetic light. Maxwell (1998) described the 'Spirit of Poverty' doctrine in which extended family members - particularly those in rural areas – making claims on their urban relations, are compared to parasitic evil spirits. This legitimises a financial strategy that prioritises the needs of an immediate nuclear family over draining, extended ties.

This double action of practical support in times of trouble, and the therapeutic reassurance that one is doing the right thing is closely analogous to approaches taken by post-HIV couples. The profound shock and rebuilding that follows trauma has encouraged new financial strategies, but also provoked new ways of conceptualising the role of money. Re-thinking and new beginnings are also important in other areas of life, as we shall see.

Love and sex in Africa

Love has often been a largely neglected topic in Africanist scholarship, though one which has blossomed somewhat over the previous decade or so (see the introductory essay in Cole and Thomas, 2009 for an overview). In contrast, much scholarship is more narrowly focussed on sex. In particular, a pragmatic, instrumental literature attempts to explain the basic outlines and trends in sex on the continent. This scholarship is of course largely driven by the AIDS crisis. In the early years of the pandemic, Caldwell, Caldwell, and Quiggin (1989), argued that Africa has a 'distinct and internally coherent system of sexuality' (187) that makes infection more likely. Whilst critics understandably rounded on the generalisations of this argument (Le Blanc *et al*, 1991; Ahlberg, 1994), others have noted that there are indeed certain trends in Africa that make the transmission of HIV more

likely. For instance, sex involving large "disparities of age between partners" (Iliffe, 2006: 62) or multiple concurrent partners (Haperin and Epstein, 2004; for a passionate dissent see Lurie and Rosenthal, 2010) are both seen as major forces in the spread of the virus.

These debates are a subset of broader attempts to understand why the HIV pandemic has affected Africa so severely (see Iliffe, 2006, Chapter 7 for a summary). Sorting out the precise role of sexual behaviour in Africa has proven a complicated task, as epidemiology is hampered by both institutional politics (Pisani, 2008: especially 13-42) and uneven statistical evidence (Minkin *et al*, 2003 and Gisselquist *et al*, 2002). Furthermore, there is often a fractious tone to these debates, with accusations of a totalising, racist view of African sexual appetites (as was the case against Caldwell, Caldwell, and Quiggin, 1989, above), meeting a perceived unwillingness to face difficult truths about promiscuity, premarital sex, and indeed homosexuality which amounts to denial (de Waal, 2006, 19-22).

As important as the debates are, they tend to treat sex and desire as mere infection vectors. Love and relationships, when they are represented, are cultural practices twisted into problematic forms by poverty and gender inequalities. Similarly, scholarship that investigates sexual violence, either in connection with conflict (Spiegel *et al,* 2007; Anema, *et* al, 2008; and Supervie *et al*, 2010) or in domestic settings (Kim, 2003 *et al*; Pitpitan *et al,* 2012; and Stephenson *et al*, 2011) are essential contributions to epidemiology, but continue to address sex only in a pathologised, problematic form.

The AIDS crisis, however, did encourage some work that investigates the cultural position of sex, often focussing (because of their epidemiological significance) on young people. Such work explores the metaphors through which young people understand sex (Undie *et al, 2007*), roles and expectations as they understand them (Wright *et al*, 2006), and the various barriers to effective sex education (for instance, Kesby, 2000b; Mbugua, 2007; and Adamczyk, 2011). These arguments retain a practical intent in tackling the HIV crisis, but enlist a far more sophisticated understanding of what kind of sex young people are having, with whom, and why. Such work

acknowledges that different generations may well think about love and sex very differently – and often approves of the more pragmatic and rational attitudes of youths (Gwanzura-ottermöller and Kesby, 2005).

Only in the last decade or so has it become common for Africanists to take not only sex, but also romance and love as objects of enquiry. This represents a rather late arrival to this academic field. Love and romance have for some time been important themes in social science. This includes historical work on the origins of love (Boase, 1977; Foucault, 1990), or influential theoretical work that connects love and romance with modern notions of self and intimacy (Giddens, 1992; Luhmann, 1986), and explores which elements of love and desire are either biological, essential and universal; and which are cultural, contingent and particular (Jankowiak, 1995; Lewis, Amini, and Lannon, 2000).

While emphases and accounts of process vary, it is almost axiomatic that sex is a key pivot between the personal and the social, an act "given meaning through unconscious processes and…cultural forms" (Weeks, 1985: 4) and a fundamental part of social and political power (Foucault, 1990). In other words, the way that sex is regulated, and the capacity of sex to both reproduce and remake society means that sex and society are always deeply enmeshed. As Donnan and Magowan argue, "the anthropology of sex is also the anthropology of religion, economics, politics, kinship and human rights" (2010:1).

Various scholars, particularly anthropologists, have explored this terrain in Africa. For instance, Andrea Cornwall's (2002) account from Nigeria's Yorubaland describes how gossip and negative labels for 'troublesome women' are acts of "control and containment" (2002:977) towards female sexuality. These same discourses also reflect and reinforce social ordering more broadly – in particular with reference to money. Anxiety about social change, norms regarding the proper acquisition of wealth, the value of family and reproduction are all to be found in discourses about sexual propriety. Sex is in the public square, and cultural values are in the bedroom.

Another crucial aspect of how sex and love are inextricable from social relations is described in Mark Hunter's work on the 'materiality of sex' – that is, sex in which transactions (ranging from one-off gift-giving to the sharing of assets within marriage) also takes place. Sex, masculinity, and materiality are tightly bound together, and economic cultural circumstances can rapidly create new forms of relationships and intimacy. Using different analytical scales, Hunter shows how these connections operate at the level of an individual community (2002), in a historical perspective (2005), or in relation to national economic trends (2007).

Similar work from Uganda (Mills and Ssewakiryanga, 2004), Kenya (Luke, 2005), Madagascar (Cole, 2004) and South Africa (Bhana and Pattman, 2011) all explore what Daniel Jordan Smith summarises as "the dynamic between interpersonal intimacy and material exchange – or, more crudely, between love and money" (2009: 164). For this study, this means that the study of post-HIV couples is in part a study of their approach to money.

Another important trend is the importance of 'modernity' to understanding sex, romance and love. Regardless of how social scientists might approach this contested concept, "notions of becoming modern continue to wield tremendous power in everyday African life" (Meyer and Pels, 2008: 1). Rachel Spronk's (2009, also 2012) work amongst the Nairobi middle class shows the complexities of love, romance, desire and sex for people who want to be 'African the modern way'. That is, to interpret, for instance, premarital sex, male lust and dating expectations through both multiple and conflicting visions of modernity, and various notions of what is to be 'traditional' and 'African'. And because "[s]exuality is a public as well as a personal affair" (Spronk, 2009: 501), a great deal can be retrieved from studying "the intricate interface of public understandings and personal experiences of sexuality" (*ibid:*502).

So, Africanist scholars at least have a well-developed range of concepts with which to begin their investigations. Two themes are particularly applicable to this study: the origins and implications of different forms of intimacy and the complex relationship between love and materiality (as discussed above).

These are the issues that post-HIV couples must wrestle with. They must begin from conventional notions of sex, love and marriage to rebuild ties into networks from which they have been marginalised; but at the same time, must adapt to new circumstances. What is required, then, is a reformulation of notions of sex, love and marriage, often drawing – selectively – from foreign, modern ideas about love.

Rethinking romance

Whilst Zainab enjoyed talking about money, she enjoyed talking about love and romance even more. In particular, my status as a single man was the source of considerable consternation, for Zainab and many others. "Why have you not married one of the nice girls from my place?" Zainab shrieked in mock chastisement. A source of both humour and genuine puzzlement, the urge to match-make for such an eligible, exotic foreign bachelor was keenly felt by many that I talked to.

Out drinking in the evening, a male friend would often draw close, to suggest to me, sotto voce, the benefits of a particular girl, bringing our drinks or tending the barbecue; whilst female friends would tell me that if I were to only go to church with them on Sunday, afterwards I could be introduced to a highly suitable young lady of impeccable reputation. Such suggestions are doubtless always made to visitors, or at least those perceived to be wealthy.

Depending on my mood, I would either playfully consider or grumpily dismiss these proposals. However, this meant that the topic of finding a partner was always near the top of the agenda in casual conversation. Relationships – how to find them, how to keep them, what they are, and who deserves them. These were all topics about which everyone had an opinion. As I began to record these impressions in more detail, I again noted a significant, consistent and predictable distinction between the attitudes of newly remarried HIV positive people, and the population at large.

"The reason, Kingsley, that you will marry my sister", Ladi explained, "is that you are a big man, and famous professor, and that you will look after her very well". Indeed, it was widely agreed that my wealth and

professional success (sadly both exaggerated) were amongst my most desirable characteristics. Zainab, however, perceived my assets differently, "You are handsome, like a US Marine", she argued, and "you are kind and always available remember to text when after my visits [to a pharmacist who would supply her with drugs]". Further discussions revealed more than simply flattery or banter – discussions about me were a reliable proxy for more general attitudes about romance. It was in these conversations that I began to realise how significant relationship aspirations were, and what sort of concepts HIV positive people used to understand and discuss their hopes.

The most obvious distinction could be summarised by 'relationship as role-based partnership' vs. 'relationship as affection-based romance', with the new relationships formed in the aftermath of HIV trauma much more likely to emphasise the latter. Many were young when they were first married, and the simple fact of being older and more experienced made them able to approach with a greater sense of volition. Over time, however, it became clear that these attempts to find and build new relationships had more complex and revealing characteristics.

An ethnography of shared movie watching

To explore love and relationships further, I developed a series of questions that I would ask during ethnographic, informal interviews, both abstract ('What do you think makes an ideal wife/husband?'), and personal ('What is the best thing about your current husband?'). I struggled to find the right tone to ask these rather intimate questions, and could not always encourage an open discussion. Discussion of the issue by proxy usually worked better – in discussing characters in films we watched together. A popular way to wait out midday heat was to watch a movie – either Western romantic comedies, or Nollywood (Nigerian) and Kannywood (Hausa films). Because of the ethnicity of the people I knew best in this context, I watched the Kannywood films considerably less than the others – but the films themselves, and certainly the way they were consumed had certain significant characteristics in common.

The interest here is not in the films themselves – and certainly Nigerian films have been widely discussed in academic literature (Haynes, 2007, for a review). Instead, what matters is the reaction and interpretations of the audience. I stumbled upon this method largely by accident. Much of my fieldwork involved spending the mornings at the clinic, or at the office of the NGO, or in meetings of various kinds. In the afternoons, particularly during the soporific hot season, I would often spend time relaxing at the houses of my friends.

At first, this was with a handful of couples that I had known for several years. As I realised how useful this 'deep hanging out' – to use the cliché – was, I gradually expanded the pool of people with whom I spent those afternoons. I was aware that I was drifting into an ambiguous space between socialising with people who I genuinely considered friends, whilst also in some sense gathering data about them – a common dilemma in long-term ethnographic projects (e.g. Hammersley and Atkinson, 1995:80-123; Murphy and Dingwall, 2007:339-351).

I decided to manage this awkward situation by electing at an early stage to write directly only about the HIV positive couples that I knew well, and had explicitly discussed and sought consent for this specific purpose of my research. They were very interested in this aspect of my research, and it was their enthusiasm for the nascent idea that post-HIV couples were distinctive somehow that encouraged me to pursue the theme. There was also an 'outer circle' - those who I had known for some time, and had a friendly relationship with, but were not especially close. With this latter category, I decided not to make direct records of the time we spent together, as I had not had the same opportunity to discuss and contextualise my research in a way that would secure properly informed consent. Nonetheless, this circuit of socialising and hanging out reassured me that the case studies discussed below are not merely idiosyncratic, but were reasonably typical of broader post-HIV patterns of behaviour.

There is a methodological tradition of watching films together in ethnography, often referred to as 'audience studies'. As Rose (2012:261-296) describes, the method has evolved from the analysis of individual responses to media, to exploring the interactional nature of the watching experience. In one such example, Michael Billig explores people who discuss the British Royal Family, with the following rationale:

> "*Important themes and issues flow through the seemingly trivial chatter about royalty. In addition, as families sit in their living-rooms, discussing the extraordinary life of royalty, so they give glimpses of ordinary ways of living*" (1998, vii-viii).

Thus, focus is on not just what is watched, but how individuals and couples watch and the kinds of conversations that it provoked.

Repetition was common in the consumption of these films. Films shown on both subscription and free satellite TV were often repeated on consecutive days, and certain movies seemed to recur several times in a month. Similarly, Nollywood and Kannywood movies are typically sold on video, CD or DVD as well as being shown on TV.   Personal video collections were often quite small, and favourites were often rewatched.

Thus the experience tended to be quite unfocussed – on soporific afternoons, fifteen minutes would pass before a friend and I would realise we were watching the same film as last week. Friends would watch the second half of a movie one day, and the first half the next, or confuse characters and events from similar but different movies. They would fall asleep, switch over to Al-Jazeera, or wander off to return with food half an hour later.

While obviously Nollywood and Western movies[60] have very different characteristics, within those broad genres, it seemed not to matter too much

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[60] I use 'Western movies' rather than 'cinema' or 'Hollywood' because the films were a mix of big-budget Hollywood films (e.g. 'The Wedding Planner', 'The Proposal', '50 First Dates', '40 days and 40 nights', 'Two Weeks Notice', and 'She's the Man') and made-for-TV Hallmark channel melodramas.

what we were watching. Films were consumed not as singular cultural products, to be considered in their entirety. Rather, they were an only partially differentiated stream of scenes, places and people. This is partly due to the nature of the films themselves[61]. In the case of Nollywood films, "most are long – at least three hours in length – and consist of more than one part (e.g. Part I and Part II, the purchase of which is not necessarily linked)" (Miller, 2012: 118).

Hugh Grant and Sandra Bullock

'Two Weeks Notice' seemed to be on near-constant rotation during my fieldwork, and I watched at least parts of the film with three different couples. It is a romantic comedy starring Hugh Grant (as a playboy billionaire) and Sandra Bullock (a feisty lawyer). Much of the comedy derives from Grant's character's selfishness and ineptitude and Bullock's character's awkwardness – which the couples enjoyed. Andrea and Michaels immediately drew a parallel with their own lives – giggling at the physical comedy, as Grant would dither half naked in a changing room, unable to decide what to wear, or Bullock would be clumsily knocked unconscious during a tennis match:

> Michaels: "These two are so scatter-scatter [chaotic, disorganised]! That guy [Grant] is always so smooth, but he can't find his clothes without his wife [sic – referring to Bullock, though they do not marry during the film]"

> Andrea: "A-a! See you now! When I saw you, your own house was in a really bad condition! You could not even find your trousers, *abi*

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[61] It is beyond the scope of my experience to judge whether Nollywood films are formulaic and clichéd – as Haynes points out, academic literature on Nigerian cinema has traditionally been somewhat divided between scholars of African cinema who are intrigued but find them "embarrassing in terms of quality and mentality" (2007: 107) and anthropologists who see the videos as vital cultural and political texts "to be read as responses to the anxieties of contemporary West African life" (*ibid.*). Nonetheless, it seemed to my untrained eye that they often returned to a consistent set of themes. Similarly – the Western romantic comedies rely on – whether in doggedly following or cleverly subverting – a distinctive canon of tropes: mistaken identity, the return of a long-lost lover, the oddly-matched couple and so on.

[right]?”

[Both giggle]

Michaels: “It's true now, you've really cleaned me up!”

No reference was made to Michaels' past, though I gathered from others that he was separated/divorced and was living alone when he met Andrea. I knew Michaels (a professional at a cement company) when he was still single, and he cared a great deal about both his appearance (usually in a suit, even in the evenings) and that of his Toyota. So I found anecdotes of his previous disarray a little far-fetched. Nonetheless, he and his new wife both enjoyed the narrative of her saving him from slovenly bachelorhood.

The reference to the romantic leads as 'husband' and 'wife' was no isolated slip of the tongue. Kebbi viewers of these films often used these terms to describe unmarried but seriously involved characters. This subtle domestication - adding the propriety of marriage to on-screen relationships – implies an active reinterpretation of ideas, rather than the passive consumption of them.

Most striking, however, was their response to the reconciliation of the couple in the final third of the film. The conflict between the two characters is driven by Bullock's idealistic lawyer trying to protect a community centre from Grant's rapacious property developer. Grant's character proves his 'heart of gold', and true feelings by protecting the community centre, even though it costs him a great deal of money. He couples this with a dramatic public declaration of his love. This act of financial sacrifice clearly resonated:

> *Andrea: “When you are with your true love, money is not the number one thing, or even the number two or number anything. You must be true…it doesn't matter what other people say about you. Let them talk. It is between the two of you.”*

Other couples also found an unexpected empathy with Grant's New York billionaire. George said:

> *"It is really doing the right thing – if you have made a promise to your darling, the money is not important."*

That is, the fact that Grant decided to use more humble and personal means alongside the use of his wealth appears to resonate with the more frugal financial ethic described elsewhere in this chapter. Grant is willing to use his money, but he is by no means simply buying love.

A subplot in the film involves Bullock's romantic rival, played by Alicia Witt, also competing for Grant's affections. Witt's role seemed to be as the charming, sweet but ultimately inadequate 'Other Woman' – a benign foil for Bullock's character. But this Kebbi audience was far less enamoured:

> *Andrea: "She is a seriously bad woman. In America, or England or Nigeria it is all the same, there are always girls who are out to steal men."*

The men were also unimpressed, reading Witt's flirtatiousness as the behaviour of a slutty, destructive seductress. I asked George what was so bad about her:

> *"She should know that he is not the right guy for her. Whenever you see a woman chasing a guy like that, it is a bad situation. You have to ask yourself, 'what is she wanting?'"*

Later, George drew a telling comparison with his former attitudes:

> *"I think that before [my life changed because of HIV] I was a really fun guy and was a bit crazy. But that is our condition, Nigerian men can be very reckless. Now I don't like these kind of girls."*

Thus, post-HIV individuals and couples are appropriating parts of the romantic forms on offer in Western media. Relationships in the movies that demonstrated a free choice of partner, and pursuing a partner because of love were commented on and approvingly adopted by the post-HIV couples. However, this was by no means a uniform switch to a Western code of relationship ethics. An emphasis on partnerships of love rather than roles is appreciated, but this does not imply a broader approval of serial monogamy.

Indeed, the couples used the movies as a proxy to contrast their current behaviour with the loose morals of their previous lives (and by extension, Nigerian society in general).

Perceived promiscuity was similarly scorned in another romantic comedy, 'She's the Man'. The movie is a riff on the gender-swapping of Twelfth Night, when promising female soccer player (Viola) pretends to be a man to develop her skills (and prove a point) when the girls' soccer team is cut by her university. The couples I watched the films with enjoyed the physical comedy of the near misses and the situational farces as Viola switched between her male and female personas, or tried to dodge the communal showers. Watching the film out of sequence and in pieces left the couples (and myself) confused about the web of jealousies and relationships amongst the ensemble, and perhaps this made it difficult for the couple to connect with the broad satire of gender roles. But as a (stylised) portrayal of dating in a US college, the audience again were critical of promiscuity, and women actively pursuing men.

I asked, however, about what Michaels and Andrea thought of the conclusion, which involves the male lead (called Duke) falling in love with Viola, despite her ending up somewhat humiliated and unfashionable after her deceptions are revealed.

> *Michaels: "Yes, it's really nice. He likes her and he doesn't care what anybody thinks about it."*

Drawing a direct comparison with their own experience, Andrea elaborated:

> *"At the time we were first together, I know that a lot of people were talking. Even in my own family, I knew that the things they were saying were very bad. But what are they doing now? It is not their choice."*

This represents a particular form of acceptance of family behaviour that was frequently mentioned by such couples. Many described how their families had distanced themselves after a HIV diagnosis. However, even when such separations took place with apparent acrimony or cruelty, the HIV positive

individuals and couples tended to avoid blaming their parents. "It is not their choice" was a common response, or "that is what our people are like".

HIV positive people often accounted for the behaviour of their families with an almost sociological detachment, and realised that they had been thrust into a somewhat new situation. Andrea again:

> *"Our country is a very traditional place, and our traditional African beliefs are very important. But we can be more modern people – why not if we have been kicked out of the house?"*

This explicit use of a traditional/modern distinction to contrast their pre- and post-HIV social situation underscores that Andrea saw the disruption of HIV as an opportunity. But it also demonstrates that she, like others, had given considerable and explicit thought to the web of social relations in Kebbi, and her position within it. This kind of explicit reflection itself closely resembles a quintessentially modern form of self-reflection, one in which "social practices are constantly examined and reformed in the light of incoming information about those very practices" (Giddens, 1990:38).

Another film, a Nollywood movie called 'Distance Between', drew similar reactions.   The two female leads are close friends from childhood, who both have a history of sexual abuse, but who are apparently dealing with their torment in different ways – Praye has become a promiscuous wild-child, whereas Mosun has become inhibited and prim.

The film has a keen eye for male deceit. Praye begins a relationship with a male co-worker, yet both are already engaged to others. He is outraged at Praye, oblivious to his own hypocrisy. I first watched the film with Jonathan, whose wife I knew, but was not present. I asked him what he thought of the male character, and whether he thought that behaviour was typical:

> *"We Nigerian men have a very bad reputation. And let me tell you, it is really true. People I know very well, sometime my childhood friends behave very badly. They could walk in here, and you would think they are very*

correct. But even if they are a pastor, they can still do these kinds of bad behaviours.

I know though, that is not the correct way to behave. I have been given this thing [HIV] – you know this from our meetings. I can't push it out, but I can behave properly. And actually, it makes me a better man. I know, of course, it can be dangerous for me to be like that [promiscuous]. But also now I have settled down. And that is the right way for me to be a man."

We talked in this vein for many hours – he was amongst my closest friends. His experiences tallied with other conversations. Being HIV positive – with its requirements to be either careful or risk passing on the disease – had made promiscuity a far more fraught option.

Very broadly, Nigeria could be said to have two frameworks for governing sexual behaviour: an overt one, that amongst both religions emphasises the need for sex to take place within marriage, and a shadow register in which other forms of relationships such as concurrent partnerships are censured but tacitly tolerated to various degrees. HIV complicates both of these frameworks. Existing, conventional, social-approved relationships may become impossible in a context of stigma and family breakdown. And more casual relationships become unacceptably risky.

It is no surprise, then, that post-HIV individuals and couples should seek to build a new framework for their relationships. This new framework is shaped by the need for partnerships that provide financial and emotional support independent of extended families. They also respond to the different needs of people who are looking for a partner whilst being older, more experienced, and more capable of self-determination than they were at the beginning of earlier relationships. These new structures are influenced by and are in conversation with Western relationship ideals, as mediated by cultural forms such as movies. This influence is a potent but selective one, as people pick and choose the ideas relevant to them. The following section

explores the appropriation and use of another form of cultural and personal guidance – self-help literature.

Self-help books and reflexivity

Another way into the lives of post-HIV couples is through conversations about what they read. By far the most widely available books in Nigeria are either religious or self-help books. Some of the books are well-known Western bestsellers such as 'Feel the fear and do it anyway' by Susan Jeffers, 'How to win friends and influence people' by Dale Carnegie, and 'The 7 Habits of Highly successful people' by Stephen R. Covey. (For analysis of such books in various eras, see Gourash, 1978; Zimmerman *et al*, 2001.) Books by evangelical preachers – most famously Billy Graham - are common as well.

Books written and published in Nigeria are even more common, often inexpensively printed paperbacks, typically quite short – between say twenty and forty pages. A content analysis of these texts is beyond the scope of this enquiry (see Newell, 2008) though suffice to say they cover a broad diversity of styles.

In the West, analysis of self-help books has focussed on several themes. One topic has been the relationship between self-help and feminism (see Hazleden, 2003 for a summary). This includes optimism for the self-help genre's role in promoting a question for female self-reliance, as well as fears that much self-help literature 'promote[s] the sexual interests of men' (Tyler, 2008: 363) by insisting upon 'gender-dichotomized views of behaviour' (Signorella and Cooper, 2011: 371). The case studies below suggest self-help literature can indeed work both ways: both to transmit patriarchal notions, but also as a means for interrogating them.

Other critiques express a Foucauldian concern that the attention of self-help literature is a part of a project of political governance. Of specific concern is the primacy given to the self, as:

"Preoccupation with mental and emotional hygiene for the soul and the mind encourages individuals to think of all behaviour as psychologically explicable in origin and effect" (Rinke, 2000: 71).

In making this emphasis, attention is deflected from social, political and economic loci of power, and an individualised, atomised version of society is inscribed upon citizens (Giddens, 1992). These are valid concerns, and in the setting of this study, structural forms of impoverishment are certainly relevant. However, the case studies below nevertheless suggest that even the marginalised find value in this individual mode of reflection, and indeed use the lessons of self-help literature to help form judgements towards wider society.

Others worry that self-help books focussing on particular health issues may not be ideal because they reproduce unhelpfully narrow biomedical conceptions of illness (see Lyons and Griffin, 2003 on menopause), or simply because they are an inadequate substitute for a professional therapeutic relationship (see Richardson *et al*, 2010 on depression). Others – ambivalent as to the consequences – point to medical self-help literature's potency in helping construct patient roles and medicalise (appropriately or otherwise) human experience (see Barker, 2002 on fibromyalgia). Still others simply argue that such books are pseudo-science, fraudulent, and have little to offer beyond psychobabble and false hope (see Bergsma, 2008 for a review, also Ehrenreich, 2009).

What these arguments have in common is the suggestion that the benign appearance of self-help literature conceals the political agendas they tacitly and perhaps even unwittingly promote. Relatedly, such perspectives also imply that these texts articulate or reflect the hopes and anxieties of their target audience.

However, these critiques are highly contextual, in that they presuppose that the texts are being read in particular political and historic locations. When texts are read in a different place, the analysis of their political payload must be renewed.

The American (Western self-help books are predominantly from the US) books that have reached Nigeria confront a much different reality. The fact that 'Men are from Mars, Women are from Venus' – as John Gray's bestseller would have it - may read less as a call for return to traditional roles amid the confusion of Third Wave feminism, but simply an elaboration on a common-sense principle; whereas the '7 Habits of Highly Successful People' will still articulate a capitalist sensibility that emphasises personal integrity, but will take on additional urgency in society in which there is "a popular sense of crisis about social morality" (Smith, 2007: 19), particularly concerning wealth and corruption.

More specifically, the post-HIV couples discussed in this chapter are interpreting these texts from a unique emotional, cultural, and spiritual position. The task, then, must be to examine how self-help books are interpreted and understood – which in turn sheds light on the concerns and priorities of post-HIV couples.

Special uses of self-help literature

Like movies, self-help books are ubiquitous in Nigeria. These books were often lying around in the living rooms of all sorts of people I visited, and they were a common topic of conversation. Asking what it was that someone liked about a particular book, or if a certain insight was seen as especially valuable, I often took the impression that although people enjoyed reading these books, they were not taken especially seriously. Authors were admired, and their suggestions were considered interesting, but the books seemed to be viewed as intriguing nuggets to ponder occasionally, rather than vital codes to live one's life by. In short, these publications were largely received in an equivalent manner to how glossy lifestyle magazines are read in the UK - that is, as pleasing diversions rather than sacred wisdom.

However, as with the movies – they were consumed in strikingly different, intense and revealing ways by post-HIV couples. In similar contexts to the shared movie viewings, I was occasionally urged to borrow a self-help book. I was often told it was a particular favourite of the lender. I rarely saw annotations written in the books themselves (though passages of text were

occasionally underlined). However, often comments were made on notepaper, and left folded in the pages. Perusing these notes, it became clear the books were taken very seriously, and had been deliberated on at some length:

> *"Speak for yourself – tell the world who you are, I do this, must say things*
>
> *The Way We See the Problem Is The Problem – change my problem, no quick fix, new level of thinking, change myself. We are what we repeatedly do. Excellence, then, is not an act, but a habit.—Aristotl [sic] Change my habits"* [Inside '7 Habits of Highly Effective People']

I noticed this trend of making thorough use of self-help books quite late in my research, and revisited many couples to try to get a sense of what it was about their situations that drew them to these texts. This opened up a series of conversations that went way beyond how particular kinds of reading materials were used. New couples suggested that they now thought about the world, and most especially themselves in quite different ways.

On one occasion, I asked one of the post-HIV husbands why most of the books on his shelf were self-help books. "These books are really nice – you should look at them. You see, we always have to be thinking about tomorrow." I asked him what he meant by this. He went on to argue that habits can be very restrictive, it's easy to get stuck doing the same things, even if they produce bad results. He cited an example in his previous marriage about how he was 'neglectful', spending too much time out at the barracks (a local drinking venue in the evening), even though he could see the deleterious effects it was having on his marriage.

I confessed that I found the books a bit unimpressive – aren't they just stating the obvious I said, telling people what they already know? He laughed, and said, "well, obvious things are sometimes difficult!" He continued, drawing an analogy with instructional preaching: "I have been listening in church since I was a young boy, and you know sometimes pastor will tell you things you have heard many times – the pastors are not professors. But it is not a waste of my time – I can ask if I am really behaving correctly".

This was a common theme – the self-help books were not so much a source of privileged knowledge, but a prompt for reflection. On another occasion, Angela (the lady now married to Simon) used a different metaphor to make a similar point. "These people" she said, tapping a copy of '7 Habits', referring to self-help authors, "are really experts, and they are the people to read. If you have a car, you need to take it to see a real mechanic to get everything fixed and checked properly. If you just take it to anyone, they may spoil it for you. Well, I am the same – I want to always be checking if I am on a godly path".

Furthermore, Angela said that she often talked to Simon about things they have read. "Well, if I see something that is important, of course I want to share it with [Simon]". I teased, asking if this was a form of nagging, telling him to be a better husband. "Well, not really! Often if I see something it will be because I recognise that it is a mistake I am making, where I am not being a good wife. If I can confess, I will improve". By talking to Simon about this, she continued, they were telling each other what they wanted to be – perhaps a kind of mutual promise and commitment. Other examples I observed confirmed this impression that, like movies, self-help books could be either an individual experience, or a shared process.

I rarely saw Maryam, the confident young professional described in the previous chapter, reading self-help literature, so it was a surprise to see her on one occasion with two short religious[62] books about marriage. I asked if the books were helpful, and received a surprising reply:

> *"I think they will be very important. There is someone and I will ask him read them very carefully and tell me his own views. If someone can be serious about this, then he can be serious with other things. But if he tells me nonsense with this little thing, then I know he cannot be trusted with much. That is what the Bible tells us."[63]*

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[62] One was entitled 'Are YOU ready to marry is His house?'
[63] I only realised much later by chance that Maryam was paraphrasing a well-known Bible verse on honesty: "Whoever can be trusted with very little can also be

The 'someone' that Maryam mentioned was a potential suitor that another KAPOP member had mentioned to her. She was using the books to vet this possible partner, and told me she had done so once before and been disappointed. In pre-marriage counselling – a very common practice in many Nigerian churches – such books were often used by a pastor to facilitate discussion. Maryam was not prepared to wait until this late into the process, and instead independently used the self-help books as an interrogative tool. This perhaps represents an interesting reversal – whereas Christian and especially Pentecostal interventions into marriage are often assumed to be patriarchal in nature, here Maryam used them for her own self-determining purposes.

Phrases like 'good wife', 'better husband', and 'good man' cropped up frequently. When I asked what this meant, the responses seemed obvious and unremarkable – being faithful, honest, working hard and so on. More interesting responses, however, came when I asked how they were trying to do things differently in their new marriages (a topic that I asked of directly with some, but only alluded to with others).

Again, the themes of pursuing a less material life, and one less connected to extended family recurred. Often this was expressed as an aspiration to what could best be called 'mindfulness'. By this, I refer to couples reflecting on their previous lives as being lived by rote, or on autopilot in some sense. Michaels told me "before [in his previous marriage] I was living my life in a very calm way. I didn't really worry about things, I was just fine doing ordinary things". I asked if he felt less 'calm' now "well, I think since I have another time [chance], I want to be very careful to make sure I am doing the right things". When I pressed further on what this meant, he said that a book he had lent me recommended an exercise in listing life goals, and the steps it would take to get there. Others confirmed this impression that self-help books were used as a way of making explicit, and sometimes question habits that had previously been taken for granted. And when it came to

trusted with much, and whoever is dishonest with very little will also be dishonest with much." (Luke 16:10, New International Version).

romance, or marriage, or work, the post-HIV couples often felt a heightened sense of self-awareness.

As with other conversations, an overarching theme was a loosening – though not abandonment - of role expectations, and an enthusiasm for working things out for themselves. But while the process was consistent across many couples, the outcome was more varied. For some, the increased mindfulness seemed to encourage couples into more daring, more equal and less traditional relationships. For others, it had urged them to be more religiously observant, and less tolerant of their more roguish friends.

Many Nigerians use self-help literature, but it is telling that HIV positive people consume these texts so intently, and much more deliberately than in previous parts of their lives. Post-HIV individuals must find novel ways of forming, maintaining and understanding relationships, in a context where the usual cultural touchstones have been scrambled, and common sources of advice (especially family) made more distant.

Whereas movies are used as a source of ideas for innovation, self-help books are used in a similar but slightly different manner. The aspirations to be a 'better husband' or a 'good wife' are particularly telling as they imply a craving for reintegration, or a renewal of social approval. Cast adrift from many common forms of advice and validation, HIV positive people redouble their efforts to study these available sources of conventional wisdom. In them, they find advice and a means for thinking through their predicaments, but also validation and reassurance that their novel relationships can be rewoven back into what is conventional and accepted.

Summary

The premise of this chapter is that the consequences of HIV go far beyond the immediate biomedical symptoms, and even extend past the immediate social reconfigurations such as stigma-driven family breakups. After a traumatic break of one kind or another, HIV positive people must move on, and (in common with other single Nigerians), finding a new partner is a top priority.

Ordinary Nigerians seeking a relationship have at their disposal a series of well-established social scripts that set out how partners should behave towards one another. But the poisoning of family ties and significantly altered financial circumstances disrupts these conventional sequences. Instead, HIV positive people must write their own dialogue and stage directions.

There is much for them to write, as these new relationships are distinctive in important ways. They place an emphasis on love-based relationships over role-based ones, which in turn reflects the emphasis they place on love over material wealth. This offers an explicit or implicit critique of many other Nigerians, who they often see as materialistic and greedy.

Most especially, they are entered into with a heightened level of self-awareness, self-reflection and deliberation. Many have been through a relationship before, often one that went badly wrong. HIV positive people are keen, therefore, to avoid repeating the mistakes they believe they made in their younger, less self-aware days. A successful post-HIV relationship requires a keen, almost sociological understanding of how oneself, one's partner and one's society works.

Reflexivity, intimacy, and love – much of what HIV positive couples emphasise is closely aligned with a particular Western, modern conception of what a relationship should look like. Indeed, the couples often explicitly think of themselves as being 'modern'. Yet disentangling what it means to be in a 'modern' relationship in Kebbi involves understanding the selective appropriation and interpretation of a range of different cultural resources.

Movies are one such common resource – it is revealing to see how they are used as a source of new ideas. As a research method, too, shared movie watching provides an intriguing way of broaching intimate topics. Self-help books are also very widely used, in many of the same ways, though in contrast to movies, they are often used in a way that indicates a desire for propriety and respectability over novelty and excitement.

Scholars in African Studies and Development Studies have long emphasised the capacity of the poor and marginalised for resourcefulness and innovation (e.g. Schmink, 1983; Chambers and Conway, 1992; De Haan and Zoomers, 2003). This chapter demonstrates that this resourcefulness extends far beyond livelihoods to include the most intimate areas of life. Even in difficult and unusual circumstances, post-HIV couples are able to creatively rework social norms, marriage and intimacy to fit their needs. That need is to find a form of relationship that both fits their unique circumstances, but that is also sufficiently aligned with conventional norms to put them on a path back to respectability.

In addition to describing the unique position of post-HIV couples, this chapter also aims to contribute to the emerging literature on love and relationships in Africa (Spronk, 2009; Cole and Thomas, 2009). Moving beyond instrumental, epidemiological and pathological views of sex allows an appreciation of the complex ways in which relationships can be 'global assemblages': they are at once deeply embedded in existing institutions and norms, but can also be ways of innovatively challenging and adapting them.

The following chapter continues this exploration of innovation and adaptation in a different direction – the financial requirements of living with HIV in the ARV era.

Chapter Six – The price of treatment – the intimate economies of the ARV era

Introduction

The previous chapter explores the adaptation required to form post-HIV couples. HIV positive people must use similarly flexible and innovative approaches in economic matters. There are two key imperatives – one is to secure a livelihood, and the other is to choose between different treatments available in this plural medical culture.

In the context of recent history, it is remarkable that these struggles can realistically hope to bring good outcomes for HIV positive people. In their book, 'Drugs into Bodies' Smith and Siplon demarcate the history of treatment activism into two periods: developing effective drugs in the first place, and then getting them into bodies. As the Introduction to this thesis sets out, a series of scientific and programmatic breakthroughs over more than two decades has resulted in both relatively effective treatments, and the means to widely distribute them. 'Getting drugs into bodies', however, often requires significant investments on the part of HIV positive people. Additionally, other forms of therapy are often required to supplement ARVs and the minimal formal support with which they are distributed.

Therefore, this chapter is not about the economics of the ARV era in the sense of the state and market institutions that have made such treatment options available (see Peterson, 2012a; 2012b for such an approach in Nigeria). Instead, it is an attempt to assume the vantage point of HIV positive people themselves, for whom the character of national and global health institutions is at best a distant concern. Whilst the process by which ARVs came to be approved, prescribed and priced is obscure at best to most HIV positive people, a number of practical concerns are far more pressing.

With subsidised ARVs available in Kebbi, many of the barriers to treatment have been overcome. Whilst the drugs themselves are usually free or very

cheap at the point of use, there are various other costs involved in seeking treatment, testing, and consultation. Furthermore, drugs are not the only therapy that HIV positive people require. Secondary infections, the side effects of ARVs, and the more general anxieties and stresses of living with HIV create further needs for treatment. These needs are often met by providers other than hospital doctors, with religious healing being an especially important alternative.

For most Nigerians, building a secure livelihood is an arduous task. HIV positive people must do the same, but with the additional costs of these various treatments. As with coping with suffering and finding a new romance, discussed in the preceding chapters, building a livelihood is a task that is greatly complicated by the breakdown of valuable family ties. This chapter traces the decisions people must make as they either try to preserve and rehabilitate these ties, or forge alternative networks.

The HIV positive people discussed here use various strategies and follow different paths in their quest for security and health. An important commonality, however, is that economic struggles are almost always interwoven with personal and social ones. In many cases, the need for a new source of income or the solution to a persistent ailment is all but inseparable from the need for self-worth and dignity.

The economics of HIV treatment in Birnin Kebbi

Since the rollout of free or subsidised ARVs across many poor countries, a number of studies have explored the economic aspects of such programmes. The human and public health benefits are obvious. The WHO reports that ARVs have saved 4.2 million lives over the last decade (WHO, 2013b), and experience in Western countries (Beck *et al*, 1998, 1999; Tramarin *et al*, 2004) demonstrates a significantly reduced burden on health services during the transition from an in-patient system to an out-patient model of care.

The societal economic burden of HIV (e.g. Anand, Pandav and Nath, 1999; Dixon *et al,* 2002), compared to the costs of treatment (e.g. Goldie *et al,* 2006; Kumarasamy *et al,* 2007), and the investments in health services that such treatment programmes require (e.g. Schneider *et al,* 2006, Yu *et al,* 2007) have generated extensive discussions. Similarly, the economics of using ARVs as a form of HIV prevention has also been discussed in economic terms (Nguyen, O'Malley, and Pirkle, 2011; Eaton *et al,* 2012; Bärnighausen, 2012). There is little dispute, however, that the global roll out of ARVs has been a major success.

The individual or household economics of ARV programmes has also received scholarly analysis. The improvements in health that HIV treatment brings can drive significant economic benefits in the lives of individuals and their families. Absenteeism at work falls sharply as treatment begins, as studies in South Africa (Habyarimana, Mbakile, and Pop-Eleches, 2010), and Cote d'Ivoire (Eholie and Nolan, 2003) demonstrate. Similar gains have been noted in work productivity (e.g. Larson *et al,* 2008, Fox, 2004).

These improvements in the workplace have been show to drive significant benefits to both HIV positive people and their employers (George, 2006, Thirumurthy, Zivin, and Goldstein, 2008). Whilst these economic improvements tend to follow a pattern of "dramatic changes occurring in the first three months of treatment and then levelling off" (Beard, Feely, and Rosen, 2009:1343), encouragingly, a major longitudinal study has shown that the benefits can be maintained over many years (Rosen *et al,* 2013, see also, Rosen *et al,* 2010). Other wider economic costs, including caring for orphans, and end-of-life care can be avoided or deferred with successful ARV programmes.

However, participation in HIV treatment involves significant and often hidden costs to the patients. A Nigerian study notes that HIV positive people as part of a subsidised programme paid around USD8 per month for their drugs, around 10% of their household expenditure, and a similar sum in addition to that for other drugs (Onwujekwe *et al,* 2009:228). While the

subsidized drugs are only a tenth of the price of similar drugs elsewhere (*ibid.*), clearly spending a fifth of household income on drugs is a major burden. As we shall see, costs prove a significant economic problem for the people in this study, even as the drugs themselves are usually free or very cheap.

Another ubiquitous issue amongst the people discussed in this study was transport. Motorcycle taxis within the city centre of Birnin Kebbi are very cheap, between N30-60 (£0.12-0.24) for a 5-15 minute journey. But for the people I interviewed living in Kebbi's more dispersed housing estates, the costs of visiting the hospital could be two or three times as much, and for those in rural areas, much more still. Studies elsewhere in Nigeria (Olowookere, 2008; Uzochukwu, 2009; Onoka, 2011) have shown that the cost of transport to the treatment site is a major barrier to adherence (though less significant that other factors such as unpleasant side-effects), whereas a Ghanaian rural study reports that transport costs are the single biggest factor limiting treatment (Apanga, Punguyire, and Adjei, 2012).

Testing costs

Another significant cost that HIV positive people in this study struggled to meet was laboratory testing. As a condition of receiving their drugs, patients were required to take several tests. An initial CD4 count[64] was taken, which was used to determine the cost of future tests and treatment. The Federal Medical Centre and Sir Yahaya Memorial Hospital in Birnin Kebbi, and four regional hospitals I visited all followed national procedures[65] (in turn based on WHO guidelines): a HIV positive patient would commence treatment if their CD4 count was found to be below 500[66]. Such patients would be seen monthly for further CD4 tests (at the same time as they collected their drugs).

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[64] A CD4 count assesses a particular type of white blood cell. Their number – the higher the better – is a measure the strength of a patient's immune system (see Aidsmap, 2012).
[65] Based on conversations with doctors and documents seen by me. Different procedures apply to pregnant women and patients with serious symptoms.
[66] Taken as cells/mm^3.

Patients in the 500-600 range would not be issued drugs, but would be enrolled in the programme for further CD4 tests on a quarterly basis.

A CD4 count of below 350 implied a weakened immune system, and further diagnostic tests were recommended, including a lung-function test, a complete blood count, and a renal function test. Whilst these tests were available at both Birnin Kebbi's main health centres, they were neither prescribed not undertaken as consistently as CD4 counts.

At least in theory, CD4 counts were a mandatory provision for enrolment in the ARV programme, which imposed an additional cost on patients. In practice, however, doctors applied the charge to patients and the requirement of the test itself pragmatically: most patients were charged N500 for the test, but I heard many instances where the charges were waived or reduced. Similarly, the requirement to have taken the test was often difficult to enforce, as the machines were somewhat unreliable, and were often out of service for a week or more at a time (though these breakdowns had become less common towards the end of my fieldwork).

The cost of the drugs themselves

During my first trip to Birnin Kebbi in 2006, the overwhelming majority of patients were receiving drugs as part of the National ARV Access programme at a cost of N1000 (US$7) per month. This fee remained consistent during my voluntary work, but by 2010 the fee had been dropped. Various other small fees, including for patient record cards and initial hospital registration fees, continued to be levied.

As a rule of thumb most patients enrolled in treatment programmes paid about the same in test fees and other hospital expenses as the drugs themselves had once cost – that is, about N1000 a month. The equation was different, however, for those with longstanding or complicated secondary infections, who required additional drugs. Unsurprisingly, studies have

shown the cost of drugs at point of use has a strong influence on adherence (e.g. Byakika-Tusiime *et al*, 2005; Crane *et al,* 2006).

I learnt from conversations with doctors that a small minority of HIV positive people in Kebbi received their drugs from outside of the state scheme.   In 2006-2007, it was quite common for patients to collect drugs from Usmanu Dan fodiyo University Teaching Hospital, Sokoto, some two hours drive away, which some patients preferred because they knew a particular doctor there. They also valued the additional privacy that an out-of-town consultation provided. This became somewhat less common over time. I also heard hearsay that several prominent people in the city sourced their drugs privately, again to preserve confidentiality, but given the high cost of the drugs, this could only be at most a very small number of individuals.

What kind of treatment is being sought?

Most HIV positive people sought treatment primarily from conventional medical providers, and demonstrated, to greater and lesser degrees, confidence in ARVs (even whilst their ability to address suffering holistically was limited). After all, the 'Lazarus effect'[67] of markedly restored health is hard to deny, whether witnessed in others, or experienced first hand.

However, this confidence does not confer exclusivity. Many HIV positive people sought to supplement their biomedical treatment in a variety of ways. Very roughly, these can be categorised into three kinds of treatment – Islam-based, Christian-based, and those rooted in 'traditional', or 'folk' beliefs. Terminology is an issue here – the term 'traditional medicine' is problematic as it "misleadingly implies a homogeneous group of medical practitioners whose practice is essentially irrational and timeless" (Marsland, 2007:753).

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[67] The 'Lazarus' metaphor has long history in HIV advocacy in the West (see Rasmussen & Richey, 2012 for a recent discussion), and I have heard it used a handful of times (presumably independent of this Western usage) in discussions about ARVs on Nigerian radio and TV news.

Instead, 'non-biomedical healing' is a better alternative. It creates a binary that might be inappropriate in other contexts where the boundaries between biomedicine and 'traditional' therapy prove to be highly porous, such when "'traditional Chinese medical drugs… [are]…manufactured into Chinese propriety medicines'" (Hsu, 2009), or when seemingly oxymoronic 'Modern Traditional Healers' in Tanzania draw their therapeutic repertoires from different bodies of knowledge (Marsland, 2007).

Nor should this distinction be taken to suggest a homogenous, universal, scientific domain to be contrasted with a subjective, local other. The supposedly objective process of generating biomedical evidence is, after all, "susceptible to manipulation by those who fund research and to distortion by cultural assumptions that determine outcomes" (De Vries and Lemmens, 2006:2704, see also Goldenberg, 2009 and Goldacre, 2013). Similarly, abstract biomedical principles can quickly become compromised and modified whenever medicine fails or has only uneven success:

> *For people confronted with medicine's abundant uncertainties and quotidian failures, there is an exchange: explanations that do not explain and ideologies that do not offer opportunities for meaningful action are traded in for—or transformed into—those that do.* (Wendland, 2012: 770)

Nevertheless, both patients and doctors in this study made a clear distinction between biomedical and non-biomedical sources of healing, and in the participatory discussions resisted attempts to directly compare the two forms of treatment. What then, is the content of the three categories of non-biomedical treatments available in Kebbi, and what might make them attractive to HIV positive people? For this purpose, each can be considered separately.

Islamic healing

Jack Tocco's (2010) excellent ethnography from Kano provides a survey of Islamic healing practices in a similar context. Here, healing is offered from two sources. Firstly 'Islamic chemists' operate storefront businesses offering

"on-the-spot consultations and prescribe natural products indicated in classical Islamic medical exegesis, such as honey, *habbatus sauda* (black seed), dates, garlic, olive oil and perfumes" (*ibid*:388). These Islamic chemists have become far more common in Kano in recent years, with thousands of new (unregulated) stores opening (*ibid.*). Such chemists were not nearly so ubiquitous in Birnin Kebbi, but there were nonetheless several in both the city centre and the outlying suburbs. Another largely separate source of Islamic healing and advice are *malamai,* Islamic scholars and teachers who offer a broad range of advice and services, including on medical matters.

An ethnography in somewhat related context (Sufi brotherhoods in Senegal) notes that "ethnomedicine in Senegal draws centrally upon, and is rationalized in terms of, Islamic doctrine", (Perrino, 2002:227). Thus, the religious healers, the *Sérī*, draw upon their high status as intermediaries with Allah, and create an intimate yet hierarchical dynamic which reassures and bolsters the patient.

The Muslims in this study tended to make occasional use of these services, perhaps having experimented with them in the past, though as we shall see, for a small number they are of greater, more regular significance.

These healers have largely been ignored by the Nigerian state, despite various historical attempts to incorporate them into mainstream health care in various ways (Last, 1986). Furthermore, such healers, along with others in the broad category of traditional practitioners may combine improvised, *ad hoc* techniques with more structured types of knowledge that are ordered and policed in ways that begin to resemble the knowledge of biomedicine (Buckley, 1985). Increasingly, such healers form active professional associations (Okeke, Okafor, and Uzochukwu, 2006).

Christian healing

In Kebbi, a predominantly Islamic society, Christian-based healing was less visible in public signs and shop-fronts, and was instead concentrated in the churches themselves, and in various bible reading and prayer meetings that

took place in private homes. Amongst the Christians I studied, almost all said that they believed in the importance of God and prayer to their wellbeing. Several mentioned that they usually said a morning prayer as they took their first dose of ARVs in the day, and almost all reported saying additional prayers during times of unusual difficulty, such as the onset of a fever, or some short-term financial strife. On other occasions, Christian interventions more explicitly focussed on healing were sought. In particular, this meant attending workshops or 'camps', which were costly, and sometimes a long distance from Kebbi.

Such support can be highly valued. As a study of Pentecostal churches elsewhere in Nigeria argues:

> *Biblical passages regarding healing provide succour and comfort, coupled with recounted spiritual experiences enacted through prayer visualization. Thus, while the belief and desire for healing from HIV/AIDS may not materialize, the sacred space, programmes and rituals provide important religious, psychological and social relief.* (Adogame, 2007)

'Traditional' products

A third and far less significant set of treatment options were those sold by various informal traders, especially around the bus station and central markets, as well as sold door-to-door by street vendors. These preparations – often sold as liquids in the same small brown bottles used for formal medical products – are very widely used in urban Nigeria (Abodunrin *et al*, 2013).

Perhaps surprisingly, the HIV positive people in this study seldom used them. The coordinator of KAPOP gave a blunt explanation for this:

> *We positive people are professors of these things, and we don't waste our time with that rubbish. If you are thinking of buying those things, you should just throw you money away because it is the same thing.*

Indeed, both doctors and KAPOP emphasised to HIV positive people the importance of avoiding such medicine – cautioning against them was a standard part of the *spiel* in the workshops I attended. Those who did admit to trying such treatments suggested they had done so out of curiosity, or because they had received them as a gift from a friend or a relative. Perhaps this is unusual to a well-versed, treatment-competent group, but such treatments were marginal at best in this context.

Making sense of alternative treatments

In what theoretical context can we place this search for religious or other non-medical healing? Firstly, in a number of contexts and diseases, religious beliefs and spiritual practices have shown efficacy as part of coping strategies, and as a source of meaning and comfort. This includes HIV (Fitzpatrick *et al*, 2007; Ironson and Hayward, 2008, Mukolo and Wallston, 2012) as well as other chronic illnesses like cancer, with one review showing that a "majority of the cross-sectional studies (31 of 36) found a positive association between spirituality and well-being" (Visser, Garssen, and Vingerhoets, 2010:565; see also Weaver and Flannelly, 2004).

Is it for this psychosocial support that HIV positive people choose to spend scarce resources on church tithe, or an Islamic consultation? Or are they hoping for something else? This is an important question after all, because as in other parts of Africa (Nxumalo *et al*, 2011, Hughes *et al*, 2012), non-biomedical healers often receive significant portions of their income from poor people.

There are several broad possibilities in addition to the religious-as-psychosocial-succour hypothesis. One is that regardless of the efficacy of a herbal preparation or a prayer, religious rituals provide access to valuable networks of practical support. Given the importance of these networks in the lives of HIV positive people in Kebbi, this appears to be at least a partial explanation for the use of such therapies.

Another explanation, however, emphasises that there are certain areas of life and vitality – often described as 'strength' – that hospital doctors are not considered to be good at addressing. This creates an opening for various other therapeutic options. This is a compelling interpretation of cost in this study, as the case studies below mention how religious providers offer a personal reassurance that doctors rarely do.

Kleinman and Hanna suggest this may be part of a much broader process, as biomedicine becomes "increasingly divorced from the practice of caregiving" (2008:287), in part due to the increasing dominance of pharmaceutical treatments. This process has elsewhere been described as "pharmaceuticalization" (Biehl, 2007), or a situation where medical "technologies became obstacles and created feelings of loss of direction" (Meinert, Morgensen, and Twebaze, 2009:207).

Relatedly, it is the social complications of living with HIV that tend to make solely biomedical approaches inadequate. As Manglos and Trinitapoli (2011) note in their study of Christian faith healers, it is precisely the multi-faceted nature of HIV based suffering that makes spiritual healing more valuable:

> *the potential dangers of an HIV-positive diagnosis include both physical illness and loss of standing within the community, and both are framed as having spiritual solutions.* (2011:119)

So, a variety of treatment options are used by HIV positive people, which address in different combinations the multifaceted challenges of living with HIV. This should be unsurprising given the ubiquity of medical pluralism in numerous contexts in Africa (Janzen and Arkinstall, 1978), and indeed the West (Kaptchuk and Eisenberg, 2001).

In contrast to many other studies, the concern here is not specifically with the content of different medical practices (though it is necessary to be aware of them), nor does to try to transcribe the hybridised lifeworlds and ontologies that make such therapeutic juxtapositions plausible.

Instead, this study aims to understand two things – firstly, to the relative prioritisation of these different techniques. That is, for example, to explore why some choose to invest in prayer meetings, whilst others place fuller faith in the hospital authorities. The subsequent section explores how it is not just treatment options that are plural and reflective of the broad psychological and social complications of living with HIV. The multiple strategies used to gather money to pay for them also reflect these constraints and anxieties.

Who pays? Therapy management group or assisted individuals

As is explored in the chapters on suffering and love, many (thought not all) of the people described in this study have been to greater and lesser degrees separated from previously existing social networks as a consequence of stigma. These separations are very often of consequence when it comes to getting together the resources for treatment. Who assists HIV positive people in Kebbi with seeking treatment, for what reasons, and what if, anything, is expected in return?

An important concept in Africanist medical anthropology for three decades has been John M. Janzen's 'therapy management group' (1978, 1987). This refers to "the set of individuals who take charge of therapy management with or on behalf of the sufferer" (1987:68), assuming both interpretative and practical functions. As Steven Feierman points out in his engagement with the therapy management group concept, it implies:

> *that healers of all kinds-whether doctors or "traditional healers" have been less influential than we commonly think in shaping states of health or in healing the sick* (1985:73)

Focussing on the role of non-professionals is certainly a useful concept for this study as it is an unavoidable reality when doctors are a powerful, but usually infrequent and distant presence. It is also a good fit with the contingencies and innovation that characterises the economic strategies

described below. Thus, foregrounding the role of family and friends as interlocutors for providing therapy helpfully "avoid[s] conceptualising health care as some sort of structural system by prioritising the endlessly negotiated strategies of afflicted people themselves" (Allen and Storm, 2012:29). Thinking of how personal networks shape treatment choices, and the financial strategies to pay for them, also emphasises that healing and illness support represents not a separate set of institutions or discourses, but rather is deeply embedded in pre-existing social relationships.

Despite the broad utility of the 'therapy management group' concept, it leaves unresolved several important issues. In particular, it is most obviously suited to situations of acute illness, where sickness diminishes a patient's independence, shifting agency to those around him or her. The extent to which this concept applies to an on going chronic illness with long periods of asymptomatic wellness is an open one (Hicks and Lam, 1999).

Another question is what sort of groups can be sustained in a climate of intense stigma. As one study in Côte d'Ivoire explores, familial support can be far more tenuous in cases considered to be embarrassing and threatening to social standing:

> *Patients with mental or emotional health problems receive help from close family members, but the afflicted and their families hide their condition from others whenever possible. For people affected by HIV/AIDS, the situation is even worse.* (Bossart, 2003:355)

In the absence or diminished presence of family, the question turns to what kind of networks – if any – take their place. In particular, to what extent was KAPOP meaningfully facilitating treatment, and the means to sustain it?

Patient support groups

From the early days of the HIV epidemic in the West, peer support groups have been an important intervention strategy, (e.g. Ribble, 1989; Kendall, 1992), and often target specific populations such as gay men (Sandstrom,

1996) or ethnic minorities (Erwin, 1999). More recently, attention has shifted
to the role of online support groups for HIV positive people (Coursaris,
Constantinos, and Liu, 2009; Mo and Coulson, 2010).

It is in Africa, however, where such support groups have become most
prominent. A largely instrumental body of scholarship has explored the
efficacy of such groups in encouraging their members to modify their
behaviour to reduce transmission risk (Parry *et al*, 2008), disclose their status
to their partners and others (Simbayi *et al*, 2007; Gillett and Parr, 2010;
Hardon *et al*, 2013), and especially to take drugs reliably (see Power *et al,*
2003; Holstad *et al,* 2012; and Luque-Fernandez *et al*, 2013 for several
examples amongst many).

A somewhat more open-ended set of studies have addressed the question of
whether such support groups can mitigate the absence of mental health
services, either by assisting members in coming to terms with stigma (Gitau
et al, 2013) or offering more general psychosocial support (Mundell, 2012;
Walstrom, 2013).

What actually goes on inside such groups however, has received far less
attention. Important exceptions include the work of Rhine (2009) who (as
discussed in the preceding chapter) has explored the importance of support
groups as matchmaking organisations. Also important is Marsland's (2012)
ethnography of a support group in Tanzania, which emphasises that a
crucial function of support groups is to act as an intermediary between HIV
positive people and whatever resources may be available to assist them. This
can be of some use, but also means that their sero-status can become
harmfully commoditised:

> *"They enter an NGO economy that values their biological status because they
> attract income from donors, but does little to enable the living that they need"*
> (Marsland, 2012:470)

This is in part because it requires a particular presentation of the membership of the group to an external actor. This phenomenon resembles the situation I describe in Chapter 3 on suffering: KAPOP's tendency to present a few of its members as 'cautionary tales', to the detriment of those singled out as examples. In the material that follows, KAPOP's activities are explored further. They do indeed try to access sources of funding on the basis of their members' biological status, but lack the capacity to do so. As with the matchmaking, however, what is more important to KAPOP's members is not the official activities of the group, but the way that it functions as a network. In a limited way, it even resembles a surrogate family.

Livelihood strategies of women

A final issue represented in the literature that is important to emphasise is the economic activity of women. Married Muslim women in Northern Nigeria are expected to observe a form of *purdah* (literally 'curtain', more figuratively 'seclusion'). This refers to both the wearing of modest clothing, and – of special relevance here – the isolation of women within their marital homes. The strictness with which this is enforced varies greatly, but nonetheless, there is a broad expectation that women should stay in the home, and generally be less mobile and visible than men. This would appear to be a significant barrier to them maintaining an income separate from male providers.

However, a body of mostly ethnographic research has contradicted this assumption. Even strictly secluded women are often involved in extremely important economic activities. Building on earlier studies of Hausa households (especially Hill, 1969; but also Barkow, 1972; and Longhurst, 1982) scholars have demonstrated that women often engage in manufacturing and trading activities to "gain revenues with which to increase their autonomy in the domestic domain" (VerEecke, 1993). These activities often go well beyond being a minor supplement to a male breadwinner's income – they are often central to a household's livelihood

(Schildkrout, 1982, Callaway, 1987). Typical activities include tailoring, perishable and non-perishable food preparation, manufacturing and trading jewellery, and the shipping and distribution of goods.

There are, therefore, a number of established and acceptable economic strategies available to HIV-positive widows. What is required for these women is a way of adapting these strategies so that they do not require the pre-existing web of contacts that comes with marriage and family.

Summary of literature review

In summary, to maintain a good level of health and well-being, HIV positive people in Kebbi must choose between a range of treatments, and formulate a livelihood strategy appropriate to their new circumstances. Many aspects of this situation are by no means unique to HIV positive people. After all, the vast majority of Nigerian households must strive to achieve a secure livelihood, often using multiple strategies in parallel. Similarly, anyone in the region with a chronic illness must find a way of meeting the related medical costs, and must also make a judgement between the various offerings in a plural medical culture.

What is distinctive, however, is that those with HIV must very often do so with little or no family support[68]. As the material that follows explores, this requires using whatever alternative networks and contacts are available to assist in making difficult therapeutic and economic decisions.

Outcomes of participatory research

As discussed in Chapter Three, I began to conduct participatory focus groups on questions of suffering. I found them to be occasionally intriguing, but ultimately frustrating as conversations tended to get stuck at a superficial

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[68] Other illness of course have also stigma attached to them in various contexts, such as leprosy and tuberculosis (Emeharole, 1987). Leprosy, however, is now curable (WHO, 2012), whilst in African settling tuberculosis and HIV form closely overlapping co-epidemics (Pawlowski *et al*, 2012). Perhaps the closest analogy to HIV in terms of illnesses that are both long-lasting or permanent and stigmatised are serious mental health conditions such as schizophrenia (Broussard *et al,* 2012).

level (as discussed in Chapter Two). The economic aspects of seeking treatment for HIV proved a much more amenable topic to this kind of research.

I followed two parallel strategies – participatory ranking exercises, and peer interviewing. Each was intended to address the limitations of the ethnography and interviews I use elsewhere, to expand the scope of the data collection, and to collect the views of people who would otherwise be beyond my reach.

Participatory ranking exercises

I spent several months (alongside other tasks) setting up a system of peer interviewing, but the ranking exercises developed quite serendipitously. In January 2011, a workshop for KAPOP members was hosted by ActionAid Nigeria, one of KAPOP's funders and supporters[69]. Held in a hall near the main KAPOP office over two days, the workshop drew a good turnout of around 40-50 members (in part presumably due to the modest *per diems* that were offered). Whilst the training addressed general themes of self-care for HIV positive people, it also included some discussion of economic issues.

On the first day of the workshop, I realised the opportunity to ask some questions of my own. I was given permission to take one of the sessions (the workshop was divided into various parallel streams), as the international NGO was also interested in the issues of personal finance that I wanted to explore. I planned a short session that evening, and delivered it the following day[70]. The conference organisers themselves were using

[69] The NGO has been a major supporter of KAPOP since 2003. A KAPOP report (unpublished) states that the international NGO, "not only provided KAPOP with funds to carry out activities but also developed the capacities of our staff to implement projects according to specification. When KAPOP faced any administrative problems, ActionAid always supported us".

[70] I was encouraged of the viability of this kind of ad-hoc research design in part by an anecdote from a university colleague. He was involved a research project studying tuberculosis (TB) treatment in Nepal. Members of the research team were attending an international conference in Nepal, during which a dispute arose regarding the competency of rural people to understand and administer TB drug regimens. The researchers took advantage of a spare morning in the conference to

participatory methods, which made it much easier to explain the methods I was using.

My aim was to get a sense of any broader patterns that I might be missing with my ethnography, and find out if there was a clear consensus in the economic priorities of KAPOP members.   As often with such techniques, the discussions that accompanied the exercises was at least as useful as the results, as ranking can "encourage a respondent to discuss why a service may be important or not…[allowing] an insight into the mental framework that different people [use]" (Fontaine *et al*, 2013:7).   I delivered the session twice to different groups in a workshop, and later supplemented it with two more sessions with KAPOP members at their office several weeks later.

The session began with a brainstorming exercise on 'what has cost you more money since you were diagnosed with HIV'. This followed a similar discussion from a previous session, so a number of headings were quickly proposed: food (which was agreed to include nutritional supplements), hospital fees, medication costs (after some discussion, drugs for tackling side effects and co-infections were consolidated into a single topic, as the prescriptions tended to be collected and paid for together). Several other categories were proposed, but only applied to a few individuals. These categories were remarkably consistent between the groups.

The views of 28 people in total were collected. After the brainstorming exercises, I asked a series of ranking questions, giving each person eight pebbles, and asking them to rank the options, using all the pebbles each time (though as the odd numbers indicate, this did not always happen).[71]

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travel out of the city, and conduct a series of rapid interviews with care providers with whom they had previously worked. They then summarised the results of these conversations back at the conference (personal communication, Ian Harper). This and other examples (e.g. Crawford, 1997:Chapter 8) encouraged me that meaningful, useful data can be generated very rapidly under certain circumstances.

[71] Similar exercises have be widely used in research Africa, often in environmental or agricultural research. See, for example Mavhu *et al* (2011) and Raymond *et al* (2009).

The results from the four sessions (two at the workshop, and two conducted subsequently) were broadly consistent, so I have consolidated the results here – full breakdowns are in the annex:

Table One - 'Which of these new costs (i.e. since HIV) has been the most significant since your illness?'		
Item	Number of pebbles	% (to nearest 1%)
Housing	99	45
Travelling to hospital	52	24
Medication costs	44	20
Hospital fees	17	8
Food/other	9	4
Total	221	101

In Table One, almost all ranked the cost of treatment as a middle priority, often giving two or three pebbles. The workshop group had a mix of KAPOP members who lived outside of Birnin Kebbi, those in the ex-urban/outskirts areas and those who lived within town: understandably, the importance of transport costs varied to collect drugs. There was also an inconsistency about hospital fees – the discussion confirmed the impression that I had heard elsewhere that hospital registration fees seemed to be charged at various levels and in some circumstances, waived.

Housing was overwhelmingly the biggest economic change – many ranked it either as their top priority, reflecting those who had moved out of family homes into other (almost always rented) accommodation, or, at the other extreme, gave it no pebbles at all, reflecting those whose living arrangements were unchanged. There was some discussion about the significance of eating well whilst taking ARVs. Whilst the groups tended to agree that this was important, they did not rank it as a significant economic factor. This may reflect the fact that although the group included individuals of various levels of wealth, none were very poor – i.e. they believed that they were either eating well before HIV, or could adjust their diet without too much trouble.

Table Two - 'Which things to make themselves healthy do HIV positive people in Kebbi spend the most money on?'		
Item	Number of pebbles	% (to nearest 1%)
'Official medicine'	79	38
Consultations with/medicines from pharmacists	54	26
'Roadside'/traditional products	48	23
Special tithes/prayer meetings/religious consultations	24	12
Other (including extra food)	3	1
Total	208	100

Table Three - 'Which of these things do you personally spend your money on to make yourself healthy'		
Item	Number of pebbles	% (to nearest 1%)
'Official medicine'	97	46
Consultations with doctors/pharmacists	94	45
Special tithes/prayer meetings/religious consultations	14	7
Other (including extra food)	6	3
'Roadside'/traditional products	0	0
Total	211	101

I then asked two questions about spending money on 'things to become healthy'[72]. I wanted to compare what people *reported* spending money on themselves, and what they imagined their peers (HIV positive people) to be doing. There are significant differences between the tables – in describing their own behaviour, the participants overwhelming said that the drugs from

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[72] I avoided the word 'treatment' as it was usually understood in a narrow biomedical sense.

the hospital – which means drugs to treat co-infections or ARV side-effects – and various consultations with pharmacists were overwhelmingly the treatments they spent money on, with several adding that they spent money on various (Christian) prayer events.

In contrast, they imagined their peers to be pursing more pluralistic strategies. This can be interpreted in a number of ways. Firstly, there could be something about the exercise that made the participant want to project an image of treatment-competent successful patients, in contrast to less successful, less sophisticated, and more superstitious others. The specific features driving this could be some combination of the format and venue of the event (either at the KAPOP office or at a KAPOP-run event that emphasised the importance of biomedical care), my own presence, or the presence of their peers.

Similarly, the participants rejected the efficacy of, and denied using, unregulated 'traditional' cures of various kinds. As I knew from observations elsewhere that such products were at least occasionally used, so their absence here suggests that this is again an artefact of the research process.

Table Four - 'Regardless of cost, which are the most important forms of treatment?'		
Item	Number of pebbles	% (to nearest 1%)
ARVs	120	55
Consultations with/medicines from pharmacists	37	17
Special tithes/prayer meetings/religious consultations	34	16
Other (including extra food)	28	13
'Roadside'/traditional products	0	0
Total	219	101

The final exercise set aside the issue of cost, and focused on efficacy. Here, there was a clear endorsement of and confidence in ARVs. One participant said to general agreement: 'It is very simple – we have all seen how the medicine can work very well, there is no question that it is the biggest [most important] one'.

Two of the four discussion groups had a Christian majority. In these groups, there were interesting discussions about the value of prayer. Several individuals said that they valued various prayer rallies that were periodically held in Birnin Kebbi, and saved up to attend them: "if there is a very spiritual event, I will definitely be there. Placing myself in His hands in the best thing I can do". Whilst some agreed, and cast their votes accordingly, others politely and sensitively dissented. The following exchange took place in one group:

> Participant A: *"Of course it is important to be godly, but is that the same as tackling this thing in your body? I think prayer must be for making your head clearer, and to be thinking the correct things"*
> Participant B: *"If you are to chase the virus around your body, then it is only His power than can do that. There is no power like God's power."*
> Participant A: *"Yes, that is correct, it is very powerful"*[73]

In this exchange (of which the above is only a short excerpt), Participant A asserts a secular distinction between a bodily cure, and psychological or mental wellbeing, whilst Participant B rejects this, asserting God's power to act directly within the body. This exchange echoed differences of opinion I heard elsewhere about the efficacy of treatment: almost everyone agreed with the importance of divine support, and although most believed that God intervenes directly in such cases, some dissented arguing that divine support is indirect.

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[73] I did not record these workshops, so these discussions are reproduced from my notes, and so will be somewhat paraphrased.

In summary, these exercises produced some useful knowledge. It is helpful to have housing, drug costs, and travelling confirmed as the most important of expenses, and to be reminded of the high esteem in which ARVs are held. It is also useful to get a sense that non-biomedical therapies are seen as a lesser but still significant form of therapy. Listening to discussions confirmed my existing impression that there was no clear consensus on the efficacy of spiritual or religious therapies.

There are significant limitations on this form of ad-hoc exercise: the number of participants was relatively small, and by no means representative of Kebbi's HIV positive population. However, the fact that the discussions tended to be distorted and different from conversations in private settings is a feature rather than a bug. The most revealing aspect of the conversations are that they demonstrate how HIV positive people feel they should comport themselves in certain settings. As material from the peer interviewing suggests, HIV positive people feel they must adopt particular strategies of self-presentation to make the most out of the economic opportunities that KAPOP offers, and to reduce the cost of treatment.

Peer interviewing

The second approach – peer interviewing – aimed to address my concerns of the representativeness of the people I talked to. I was aware throughout my fieldwork that I was inclined to understand things through the filter of my experience of KAPOP. I actively cultivated connections to HIV positive people outwith KAPOP, especially through a handful of doctors who suggested to their patients that they contact me, and indeed steadily built up a range of contacts.[74] Nonetheless, my 'sample' (in a broad sense) remained heavily biased towards KAPOP members: I tended to meet a steady flow of new KAPOP members, while new non-KAPOP HIV positive contacts were often a slow trickle.

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[74] Just as KAPOP is only part of the HIV positive population, so were those who were referred by doctors of course. Inevitably, many who chose to conceal their status remained invisible in this study.

Many HIV positive people – both KAPOP and non-KAPOP – knew other HIV positive people. Sometimes they were close friends who had revealed their status to one another, and other times they were acquaintances who had met each other at the hospital collecting drugs once or twice two often for it to be malaria or some other disease, and had been able to broach the subject.

From the HIV positive people I already knew, I recruited[75] five – three women, and two men, as field researchers, and I asked them to talk to the HIV positive people they knew. Three of my peer interviewers conducted three interviews each, another did four, whilst a final researcher – a KAPOP member with a degree from the Federal Polytechnic and some training in research methods – did eight of a total of twenty-one interviews. I asked the peer-interviewers to interview people outside KAPOP where possible. In all cases, the interview and interviewee were of the same gender.

In particular, it expanded the reach of the study in two directions: it allowed me to gather more data from women secluded in households beyond where I could acceptably visit[76], and it also allowed me to talk to various men, especially more successful professionals, who did not want to be associated with KAPOP.

I gave the peer researchers some basic training in research methods. This mini-syllabus including confidentiality, explaining the purpose of the study and how data would be used, selecting a suitable venue (in all but one case, the interviewee's home) note-taking, techniques for asking questions and so on. Over two group discussions we came up with a series of interview questions starting from the broad topic of 'Money and living with HIV', coming up with a series of questions.

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[75] I paid for a 'meal' for the interviewer and interviewee to share – though I did so at a fairly generous level so the payment could be a form of *per diem*, if the peer interview so chose. I also covered the travel expenses of the interviewers.

[76] I discuss the concept of women living in *purdah* in the introduction – whilst this applies to all married Muslim women, the divorced and shunned tended to occupy a more ambiguous position, meaning I did have some direct access.

I also asked my peer interviewers to do two trial runs each, one with myself present, and one with me absent. In general, the peer interviewers were good at asking sensitive but direct questions, and following-up to keep the conversation on track, and after some practice, explained the purpose of the research diligently.

This latter process of interpretation, along with the expanded access, was the primary motivation for using this method. Having the peer interviewers both ask questions in ways that made sense to them, and have them explain to me what particular euphemisms or silences implied was immensely valuable. In the better interviews, the process was approaching some participatory ideal in which once I had given an overall prompt of 'living with HIV and money', the process of asking questions and analysing responses had been handed over.

These successes tended to be outnumbered by a series of failures (albeit productive ones). The 'failures' largely came about because although most of the interviewers appeared to have interesting conversations, they proved to be difficult to reconstruct afterwards. Though all the peer interviewers I chose had good literacy (which was part of my criteria for selecting them), the difficult skill of note-taking understandably proved a major challenge. I began meeting the peer interviewers as soon after the interviews as possible, to supplement their notes. This helped to a degree, though it still seemed that the method yielded a series of isolated facts and anecdotes that were hard to properly interpret out of context.

It also became clear that most of the interviewers tended to strongly impose their own views on their subjects[77]. This was also a difficult situation, as

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[77] This was evident in the responses I received – I would ask specific questions about, say, a widow that was interviewed, and only receive general responses (e.g. 'well, the situation with widows in Kebbi is like this…'). There was also a certain level of distain for some interviewees ('Well, Patience has always been a lazy woman, so I am not surprised that she is failing with her business…') that seemed to

their role as interpreters of the material was the primary purpose of the exercise. However, it was hard to get past a persistent editorialising and foregrounding of the interviewers' own views to a more balanced account. What emerged was often a set of rather gossipy (and often scurrilous) anecdotes and sketches of everyday life with HIV.

While this was not the clear picture of economic decisions amongst HIV positive people that I had hoped for, they were nonetheless useful in other ways. Indeed, these discussions nourished my own understanding of all topics in this thesis – in particular, the stories emphasised the importance of love and remarriage. I also picked up a good deal of useful practical advice on how to set up a meeting discreetly, and when the best time to meet with different people was, and so on.

Ishyaku

One of the first peer interviews was with a man called Ishyaku who I had heard mentioned several times, but had not been able to meet myself. He was acquainted with a handful of KAPOP members, but was not himself a part of the group. The peer interviewer knew him as they had attended the same prestigious secondary school in Sokoto together. Both were in their early fifties. Ishyaku worked as a middle-to-senior ranked civil servant, and his HIV status was not widely known within his family.

By far Ishyaku's biggest economic concern was the precarity of his role as a provider. Given his prestigious role, he was expected to provide for not merely his own extended family, but also to help support a wider network of people 'from his village' (i.e. sub-ethnic affiliates). The interviewer reported that Ishyaku repeatedly used the phrase "there are so many things pressing on my head" to describe this situation.

It was easy to imagine this situation – the well-off people I knew in Kebbi would frequently receive visitors in the evenings who sought assistance of

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reflect personal prejudices (albeit often interesting ones) rather than the conversations that took place.

various kinds. He could afford the cost of HIV treatment and associated consultations – though he incurred additional expenses travelling to Sokoto to collect his drugs in relative anonymity rather than go to the hospital in Kebbi. A far greater concern was that he would not be able to work, or would be forced into early retirement[78] because of ill health.

He suffered from persistent headaches and fevers, which he took to be linked to his diminished immune system, but which doctors had been unable to satisfactorily treat. He said that he had consulted an Islamic healer (also in Sokoto), which had initially been successful. The relationship with the healer, who prescribed the recitation of particular Qu'ranic verse, declined over time however, as the healer asked for larger and larger fees. "He always calls after *Fajr* [morning prayer] to disturb me", Ishyaku reported.

Although Ishyaku was frustrated enough with the healer to cut off contact with him for a while, he was considering seeing him again on his next visit to Sokoto. When asked why, he said that at least the healer was 'reliable' (*'yardaji'*). In contrast, doctors "just give you the drugs then push you out". I asked the interviewer what Ishyaku meant by 'reliable': he said it meant 'trustworthy', in the sense that he was not worried about the healer breaching confidentiality. The implicit contrast is with hospitals that are busy places where a well-known individual is very likely to bump into acquaintances. Furthermore, the healer was 'reliable' in the sense that he could always be reached by phone ("he always picks me calls", said Ishyaku), ready to offer reassurance should Ishyaku feel unwell at work.

In short, Ishyaku was unhappy with the price he had to pay for this therapy. But he did not see the therapy itself as dubious. Indeed, he was willing to pay considerable sums precisely because the healer addressed his central concern: the precarious nature of his livelihood. Ishyaku's case also confirms a suggestion that was often made to me: individuals with good

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[78] Nigerian Federal civil servants theoretically must retire at 60. State governments usually follow these guidelines, though there are various exceptions amongst the states (Casey and Dostal, 2008).

incomes were sometimes paradoxically in a more precarious position than poorer people. Or, at least, the number of dependents that wealthy people tended to accumulate meant that sudden losses of wealth were more conspicuous and embarrassing.

Gloria

Gloria talked with one of the female interviewers who knew her Pentecostal church congregation. Gloria had come to believe, like many in Africa (e.g. Eves, 2003; Roura *et al*, 2010) that her HIV could be 'cured' by prayer. Gloria was vague about what exactly she meant by 'cure', but she expressed a belief that prayer could give her a "final answer" to her HIV problem.

She had twice travelled to Kaduna (a day-long, expensive journey) to attend a five-day prayer event. I had heard others attending similar events, which were not specifically aimed at the sick, but often drew those with acute problems of various kinds. She worked as a secretary at a local college, and her attendance at these events had caused friction with her employer. Apparently, she would often book her leave in advance, but last minute rescheduling of the prayer events and travel complications meant that she had twice returned to work late.

The interviewer herself believed in the importance of prayer, but wanted to know why Gloria was spending so much of her income and risking her job (or at least, good favour within her workplace) to attend these events. Gloria asserted the importance of these meetings: "The medicine is one thing, but I know you have to take it every day for the rest of your life. Can I do that when I'm an old woman?".

When Ishyaku had spent money on religious consultations, it was in pursuit of a psychosocial supplement to cold, impersonal hospital services. Gloria hoped that her investments would yield something different, a more concrete solution to the daily drudgery of taking pills. I asked the interviewer if she thought Gloria was wasting her money, and received a

pithy response: "If I pay money to see my team Manchester United in the restaurant[79], and they lose, have I wasted my money?". It seemed that Gloria's investment in the prayer meetings was in part a way of buying hope, as with a lottery ticket, that has a value that is not wholly reducible to the final outcome.

It also suggests that there be no one simple reason why people choose a particular treatment. Van der Geest (1997:904) proposed that traditional therapies in Africa remain popular because they involve some combination of seven dimensions: a social character, a religious aspect, a preventative orientation, a holistic approach, personal attention from a healer, secrecy, and payment. Whilst prevention does not really apply in this case, this is otherwise a useful typology to think through varied motivations for therapeutic choices. A prayer meeting provided both social support and spiritual guidance to Gloria. Meanwhile an Islamic healer offered close attention to all aspects of Ishayku's suffering, and his fees (whilst irritating) tended to underscore his value. Finally, the fact that there is often a certain embarrassment in disclosing these therapies implies that they have some secret social life that lends them prestige and power.

Reflections on KAPOP

Another topic in these interviews that received extended, illuminating discussions was the role that KAPOP itself played in supporting livelihoods. These observations cut across multiple interviews, so I draw them together here, alongside observations of my own.

Throughout this interview process, and indeed throughout all my visits to Kebbi, there was widespread scepticism regarding the level of service KAPOP offered to its members. Most shared a broad understanding that during the years after its establishment, KAPOP quickly became well known as an important advocate for its members, and soon came to the attention of

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[79] Birnin Kebbi has a number of 'restaurants' (not all serve food) which charge an entrance fee to watch televised football matches.

national and international organisations looking for a partner. However, whilst its founding coordinator had been effective and ambitious, he was also accused of – at the very least – mismanagement[80]. His replacement, in office from 2005 until the present, is seen as a more reliable figure, but many questioned whether he had the required leadership skills and experience for the role.

The KAPOP coordinator's office. The cabinets and shelves (both in and out of shot) contain hundreds of documents – often reports or handbooks from NGOs which are rarely, if ever, read.

From the point of view of KAPOP's members, that role was to tap into whatever resources were available from 'above' (i.e. NGOs or the government), and disburse those goods amongst KAPOP members. This

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[80] Many within and beyond KAPOP accused the founding coordinator of appropriating funds. Although he left KAPOP, and subsequently Kebbi state, he has remained active in HIV advocacy.

sometimes meant bags of rice or beans, on rarer occasions it included equipment intended for starting a business – such as sewing machines or food preparation equipment. These provisions, however, were infrequent, and typically came only in small amounts[81].

This very limited level of provision was in stark contrast to the funding proposals KAPOP sent off, which promised programmes to encourage 'entrepreneurship', 'self-reliance' or 'business skills' amongst its membership. Whether or not these skills would have been useful is a moot point, as KAPOP simply lacked the ability to teach them.

One of the interviewees gave an account of a training session in which KAPOP and an NGO taught business skills to HIV positive widows. This involved setting up a mock stall for selling fruit, and inviting members to discuss what would make the stall successful. "They think we are stupid people", reported the interviewee, capturing a broader opinion that the supposedly participatory training made patronising assumptions about the kind of skills the women already had. This view was a widely held one: almost every activity that KAPOP did was billed as 'participatory' or 'empowering' of its members. But in the inexperienced hands of the KAPOP leadership, unfortunately this often meant a top-down, condescending style unsuited to sharing knowledge.

In summary, on the official level of what KAPOP was 'supposed' to be doing, its contribution to the livelihoods and financial security of its members was minimal. Nonetheless, in less obvious ways, KAPOP could be an important economic resource for its members. Several women in the interviews remarked that in their businesses, they often traded amongst other KAPOP members as their first customers. Similarly, in the case of those who traded in roadside stalls or small shops, they often relied on

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[81] On one occasion the state government donated a single 20kg bag of rice – clearly if this was to be divided even amongst the very poorest of KAPOP members it would not go far.

KAPOP members to cover their absences when they needed to travel or run errands.

As with those who used the support group to find a romantic partner, KAPOP's official activities seemed far less important than the networking opportunities it provided. One of the interviewers herself remarked "If I was back in my own place[82], I would be asking my sisters and cousins to help me, but now I ask the KAPOP women – they are my family now".

Summary of results from participatory methods

In summary, in spite of its limitations, peer interviewing and ranking exercises elicited some useful information. The methods revealed clear consensus on many issues, such as the importance of housing costs, the efficacy of ARVs, and KAPOP's limited capacity as a provider, but usefulness as a networking organisation. On other issues, such as exactly what religious consultations and therapies were for, and how effective they were, there were more divergent views.

Using these methods was a fascinating, if time-consuming and difficult experiment. I leveraged the fact that many KAPOP members had familiarity with participatory tools in aid of my own research. However, as the project progressed, I became concerned that my own use of these methods might begin to mirror the dominating, disempowering form of misuse that KAPOP was prone to practicing. In Chapter Two, I explored at greater length this difficulty, and the necessary and hard to avoid paradoxes involved in practices participation in either development programmes or research.

Ethnographic case studies

In the new terrain of the ARV era, HIV positive people must work out how to gather money, and which of a range of treatments to spend it on. In doing so, they are required to explore multiple strategies, often in parallel to ensure

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[82] The interviewer had moved to Birnin Kebbi from another town after the collapse of her marriage.

their health and economic security. Tracing these activities through their lives and personal histories, therefore, is an important complement to the process of ranking the importance of different activities.

The two biographical profiles presented below illustrate important recurring themes in this process of experimentation. Both are small business owners of different sorts, who have turned to trading to build more secure livelihoods. They also foreground the ways in which concrete economic strategies are frequently interlaced with efforts to rebuild or preserve a sense of self-worth.

Amina

Amina was a widow in her early 30s. Shortly after the death of her husband, she fell ill, took a HIV test, and discovered her own sero-status. She was referred to KAPOP shortly after I began volunteering there in November 2006. Her initial involvement was discreet, and she spoke little English, so I only got to know her some months later. In many ways she exemplified the ways in which KAPOP members (if not the KAPOP's official activities) worked as a supportive network to provide both reassurance and resources.

In the first year or so after her husband's death, Amina's financial situation was relatively stable – she was able to continue living with her two children in the large house she shared with her late husband's brother and his family. However, at some point in 2006 the family house was sold[83], and she had to find somewhere else to live with her children. She moved in with her own brother's family, also in Birnin Kebbi, but Amina's brother had only a modest income, and was struggling to support even his immediate family. Amina urgently needed to find income.

Even before the death of her husband, Amina had been involved in various forms of home-based trading. She stepped up these activities – primarily

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[83] The reasons for selling the house were unclear, and Amina was reluctant to discuss the subject. Several KAPOP members said that it has been a case of stigma, and that Amina's brother had asked her to leave because he blamed her for her husband's death, but another said that Amina's brother-in-law had fallen on hard times, and that his decision to move away was unrelated to Amina's HIV status.

making items of jewellery from wire and beads, but also sometimes plaiting hair, and assisting in food preparation for special events. This income was useful, but barely able to cover the basics of food and clothing. She had been referred to KAPOP for help with her medical expenses, but also because she said she was struggling to take her medicines properly on an empty stomach.

On her arrival at KAPOP, she was given small bags of beans and rice to cover her immediate needs. She was also asked to come for 'counselling' with one of the senior women in KAPOP. The term 'counselling' (used even in Hausa conversation) had been adapted from an ActionAid funded project which ran in 2005. In this project, dried foods and nutritional supplements were disbursed on the condition of patients receiving treatment adherence counselling.

Writing the evaluation reports for this programme was one of my first tasks as a VSO volunteer, and I was initially discouraged by how seldom ActionAid's guidelines were followed: rambling, unstructured conversations took place in KAPOP's sitting room, often with other members dropping in and out, followed by the counselled member writing their name (or having it written for them) on a printed list to collect their goods. ActionAid, in contrast, recommended structured, confidential advice about the importance of nutrition and other health topics.

The entrance area and sitting room in the KAPOP office provided a comfortable space for members to come and sit, and often to nap to avoid the heat of the day.

In time, however, I realised that this more discursive style was valuable. Often new members did not want specific advice or guidance, or even to talk through their problems. Instead, what was useful was to hear stories of how other people had coped with problems, according to Amina:

> *When [my HIV diagnosis] happened, I was very disturbed. I did not know what was going to happen, whether I would just get thin and die, or where I would find money to live. But the KAPOP people have so many stories. Everyone has really suffered but they are still going[84].*

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[84] *"Lokacin da labari ya zo mini cewa ina dauke da wannan cutar di na shiga matukar damuwa kwarai da gaske, ban san abinda zai faru gare ni ba, ina tsammani cewa zan fara ramewa ne har na mutu, sannan ga tunanin yadda zan samu kudi na rayuwar yau da kullum, amma labarin Yan kungiyar KAPOP yana da yawa, kowa ya sha wahala, amma gashi duk muna raye".*

Amina added that it was a particular comfort to speak to women navigating the same process of widowhood as her, especially as these women also had experience dealing with economic situations similar to her own.

In February 2007, Amina was in a particularly difficult spell, as one of her children had been repeatedly sick with malaria. The coordinator of KAPOP gave her a small amount of money to pay for a set of drugs, but also said he would find some more income for her. The next month, KAPOP disbursed a series of machines for grinding corn and sewing machines to its widowed members, which had been purchased via a grant from the US Ambassador[85]. Amina was allowed to 'jump the queue' ahead of members of longer standing, in light of her acute need. Still using the sewing machine three years later in 2010, Amina was grateful:

> *It was really nice, I could never buy a machine myself, and now it means I always have some reliable money. They definitely helped me get started and make sure I had people [customers] coming to me. These days, I know I that I can pay my hospital bills, and buy [mobile phone] credit when I need it[86]*

Indeed, as in several other cases, KAPOP and its members did a good job not only giving Amina the capital to start her business, but also the 'soft skills' (she already knew how to use a sewing machine) required to make money – recommending potential customers to her initially, advising her not to charge too little, and encouraging her to include a slip of paper with her handwritten mobile number in the bag when she returned the mended clothing, to build word-of-mouth custom.

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[85] The grant was part of the US Embassy's long-running 'Special Self-Help Program', which disburses small-grants to community groups and businesses.
[86] *"Yana da matukar ban shaawa sosai saboda ban taba tunanin mallakar keken dinki ba, amma yanzu kaga zan fara samun kudin magani da kuma na sayen katin waya idan na fara aiki da shi, mutane zasu dinga kawo mini aiki, wannan ya taimaka mani kwarai da gaske."*

By 2010, her tailoring work was providing a steady income, and she was even able to offer work as an apprentice or assistant to another woman during busy periods. However, at this time she also had quite serious skin problems, which were very painful, and she did not always trust the advice she was getting:

> *"I'm not really sure about the doctor [at the general hospital], sometimes he will give you a [prescription] paper and you can spend up to N200 [£8] and nothing will happen. Do they really know what they are talking about?"*[87]

Amina knew that I was friends with many doctors, and perhaps for this reason, she was circumspect in discussing the other treatment options she had sought. Nonetheless, I heard from others that she had paid money for a lotion from a Muslim healer, and was known to try various other remedies she bought on the street. What did she think was causing the skin problems?:

> *"I am so busy these days, running around to buy cloth and to go to the market, and people are always calling me, there are so many problems on my head. I think I am getting too hot and that is the problem."*[88]

Amina, then, described her skin problem as somehow stress-related (by no means an implausible assumption). In a discussion with two female KAPOP members, they respectfully discussed her problem. They agreed that, yes, she was indeed working very hard, which can cause problems for the body. They also said they had heard many cases where HIV positive people had struggled with similar problems. But did Amina know, the KAPOP members wondered, that some of the creams available from the hospital

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[87] *"Gaskiya ban gane wannan likitan ba saboda wani lokacin zai rubuta maka magani wanda zai kai kamar naira dari biyu amma ba wani sauki, ina ganin basu san abinda ke faruwa ba."*

[88] *"Aiki yayi mani yawa kwanan nan, ina kaiwa da kawowa wajen sayen yadi ga kuma zuwa kasuwa, gashi kuma mutane suna yawan kira na ta waya, gaskiya na fara gajiya, wannan shine matsala ta yanzu."*

gave skin strength?[89] Had Amina heard about Patience, they asked – she went to the doctor only last month, and her face is looking much better already.

By listening in a non-judgemental way to the understandings of their members, and relating them to concrete examples, KAPOP members were often able to gently steer people like Amina back in the direction of efficacious biomedical treatments. Perhaps more importantly, they were able to take what was a frightening and unfamiliar experience – both the skin problems and the need to find a new livelihood – and normalise it.

Aliyu

I first met Aliyu on Boxing Day, 2010 at the stall where he sold mobile phone accessories. It was a chance meeting, as Aliyu, in his mid-twenties, was idly chatting with a mutual acquaintance, Richards, that I knew from KAPOP. As was often the case during my fieldwork, the purpose of the introduction only became clear some time later.

His shop, one of many on the road to the Dukku Military Barracks, (also near the Federal Medical Centre) was a convenient spot to wait between appointments on the southwest side of the city, so we spent much time there getting to know one another. Gregarious and hyperactive, Aliyu would pace and fidget, and mix in unpredictable scattershot fashion anecdotes from his childhood with gossip, or an incident he witnessed earlier that week.

Aliyu told me he was an orphan, and that he never knew his birth parents. He was born in Gusau, in neighbouring Zamfara state, and was adopted by a family there. They later moved to Birnin Kebbi when Aliyu was an infant. His new family made sure he completed his primary education, but their financial situation deteriorated when his adopted father passed away when he was 12, and he was unable to continue his schooling. At this point, Aliyu

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[89] Indeed this was literally true: steroid based creams were commonly prescribed for such ailments.

said he was expected to either bring an income home, or to leave and fend for himself.

For several years, he moved to Kano, where he worked as a construction labourer, but said that the cost of living there meant that he was better off back in Kebbi. Since 2006, he had been working in various informal jobs – often in construction as a labourer, and as a carpenter's assistant, which paid better.

Around the time Aliyu moved back to Kebbi, his adopted mother remarried. Aliyu had a somewhat distant relationship with his new step-father, but nonetheless, they went into partnership together to set up a mobile phone shop in the centre of Birnin Kebbi. This was only in operation for a few months – Aliyu said that the high rent meant that the business was not sustainable. Cash flow, too, was a problem, as it was difficult to get the credit to stock the handsets, especially as more expensive smartphone models became popular.

Although this period was all too brief, Aliyu enjoyed the work. It was far more prestigious than the employment he was used to – he finally felt he was making use of his English, which was much better than most with his limited education. Even though his step-brother did most of the customer-facing work, Aliyu nonetheless enjoyed wearing the smart shirts his father provided him with, and enjoyed meeting the often young and fashionable clientele that sometimes visited their burgeoning business.

One such young and fashionable customer was 'the most beautiful girl in Nigeria' in Aliyu's telling, a student at the nearby polytechnic college.   They become involved, and thought he knew the relationship could not last (she was due to move back home shortly after graduation) he nonetheless fell in love. In spite of what came later, whenever he spoke of her it was with a cracked smile of nostalgic affection. It is this relationship, Aliyu assumes, that led to his positive HIV test in early 2010. At the clinic, the doctor

recommended that Aliyu discuss his future with a KAPOP member who occasionally took on such cases.

Aliyu never revealed his HIV status to his parents directly, but after his status was discovered (a routine test performed as part of a consultation for suspected malaria), there was a tacit understanding about his situation. He was not in disgrace *per se*, but his family were concerned about what his new illness would mean for them.

His step-father, however, helped him set up his new stall near the barracks. This represented mixed progress. On the one hand, he had a business of his own – it was technically owned by his step-father, but he was solely responsible for running it. He shared his profits with no one, except a cousin who occasionally filled in for him whilst he ran errands. On the other hand, the location was less prestigious, and phone accessories were nowhere near as profitable to sell as the phones themselves.

Aliyu's profits were modest, during lean weeks barely reaching a subsistence level. However, the most difficult part of the arrangement for Aliyu was not so much the decline in income compared his work in the city centre shop, but a new and less agreeable form of dependence:

> *"Now, I really need him for everything [my step-father]. If I am running low [of stock] here, and I need to visit him, if I am running low [of money to pay bills] at the hospital I need to visit him. Every time I am running low he is the only one I can ask."*

Financial dependence on relatives is common in Northern Nigeria, whether in the form of parents investing in their children, or forms of intra-family loans and savings (Udry, 1990). Nonetheless, this particular form of dependency rankled Aliyu – his two brothers borrowed money from their father (Aliyu's only sister was married and had moved away), but he felt that he was treated differently, and made to 'beg', as he put it, when asking for money:

"It is very difficult being a young man here, and my brothers are always asking for something. But I must be the one who says 'please, I am really not doing fine, I am weak, I need to drink medicine', or 'please, I need to buy new things to sell'."

Aliyu did not blame his step-father for deliberately singling him out, and he felt lucky to be part of the family and entitled to support at all[90]. Nonetheless, he felt that his family and especially his stepfather saw him differently since his diagnosis:

"It is a very difficult, crazy situation now. I don't know the reason – sometimes it is difficult to say the truth. I sometimes have to talk about a hospital bill when I need money for the shop, and to talk about the shop when I need to buy medicine."

This troubled Aliyu greatly, and he often spoke of a wish for greater independence. The relationship with his step-father had become a network of guilt. On occasion, Aliyu felt obliged to 'perform' his (unnamed, in this context) illness, to emphasis his neediness in order to borrow money. "I don't want to be weak and tell them I am really suffering, but that is what makes them listen" he said. Aliyu regretted this, but it was the only way he felt he could make his father support him.

Unlike with many, there was no dramatic break with his family, but rather a slow coarsening of the relationship into something less affectionate and more instrumental. Indeed, even the location of his stall, in the 'Sabon Gari[91]', implied that Aliyu was being kept at arm's length: "Even though I still sleep [in the family home] most days I can't be seen there until after dark. I move in the night, like a thief".

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[90] A number of studies explore how Hausa families can be diverse and flexible – for example Goddard (1973) and Lewis (1998).

[91] Literally 'strangers' or newcomers' town', is a section in most Hausa cities, set aside for non-Hausa – i.e. Southerners and/or Christians.

If Aliyu's relationship with his family was chipping away at his pride and dignity, his reasons for not seeking support elsewhere were understandable. Aliyu knew of KAPOP through our mutual friend Richards, and generally had a positive opinion of the group's work:

> *"Richards is very helpful – he know the medicine very well, and I know that if my stomach is paining me, he will know if it is a serious thing. He really knows how to keep his body strong with packets and things"*

The packets were nutritional supplements that had been distributed to Richards and other KAPOP members. Aliyu hadn't tried them, but nonetheless admired them as a symbol of Richards' expertise in treatment and personal care. Nevertheless, he had no interested in joining KAPOP:

> *"I know that there are so many widows and women inside KAPOP who have just nothing. But I have to be a businessman in this situation"*

There were other reasons why Aliyu didn't want to join KAPOP – participating in meetings would give him access to the occasional benefits that trickled through to KAPOP members, but would mean making his HIV status more widely known. In his self-image as a businessman, it was one thing to participate in a bilateral partnership of guilt, with the private shame that that entailed. But he felt that in the economy of pity and disclosure at KAPOP, it would be trading away too much of his pride for a small loan and some bags of rice and beans.

Analysis

Both Amina and Aliyu relied on those around them to inform their economic and therapeutic decision-making. In both cases, their options were framed by the decisions of their respective families – rejected completely in the case of Amina, and kept at arm's length in the case of Aliyu. Amina, more than many, was able to make a clean break and use the networks within KAPOP to both gain economic independence and get sound advice on treatment

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options. For Aliyu, there was a more fraught engagement with his family that allowed him to improve his economic security, but often at the cost of a relationship that threatened his sense of self-worth.

In both cases, and many others, the battle for financial security and good treatment options is fought alongside the struggle for self-worth and personal dignity. Some, like Amina, are able to find relationships and networks that allow those goals to be pursued together. Others, however, are forced into difficult trade-offs and choices.

Summary

This chapter reflects on two questions – how do HIV positive people choose between the various therapies available to them, and how do they gather money to pay for both these treatments and their other living expenses.

In terms of maintaining an income, HIV positive people modify ordinary livelihood strategies to fit their new familial and social circumstances. For some, like Aliyu, this means an uncomfortable process of negotiating with relatives. Others, like Amina and some of those who took part in peer interviews, are able to find alternative networks of customers and business advice through networks of other HIV positive people. Once again, experimentation and adaptation are key strategies for securing wellbeing in the ARV era.

There is a disjuncture between how donors perceive KAPOP, and how its supporters use it. Whereas officially the support group offers a range of services, training, and more vaguely defined 'empowerment', in reality these activities (typically in the form of workshops) were not well received. In contrast, the informal networks that KAPOP fosters – only partly by design – are indeed valuable. A greater recognition of this hidden, informal role might help their donors engage with support groups more productively.

The process of making decisions about treatments can be divided into two parts. Firstly, there is broad confidence in ARVs and the doctors that

provide them. The participatory ranking exercises and the discussions that accompanied them made this clear. Whilst the drugs themselves are now usually free, the expense of travelling to hospital, various hospital fees, and costs of secondary treatments for side effects or co-infections are a significant burden.

Secondly, it is equally clear that these biomedical treatments only partially address the therapeutic needs of HIV positive people. Those such as Ishyaku and Gloria felt themselves in need of additional support from religious providers. They sought relief through healers or prayer events because what they got from the hospital left gaps. The nature of these gaps varied from person to person – for some, it was the need for a more personal and reassuring consultation than hospital doctors were able to provide. Others had more profound concerns and, daunted by the requirement to take drugs for life, sought divine intervention.

Thus, these religious therapies are valued because they provide either a form of psychosocial support, or because they hold out hope for a more profound intervention. In contrast, non-religious, 'traditional' therapies were generally disdained.

The tasks of both making drugs, and then of getting them into bodies has been accomplished in many cases. But that so many in Kebbi seek out supplementary therapies is revealing. It confirms that the ARV era has emerged in contexts with highly plural medical traditions. It also suggests the limitations of the hospital-based care: the motivations for pursuing non-biomedical care can be read as a list of everything that is not provided by doctors. These omissions may be because of scare resources (and the consequent infrequent, rushed consultations at the clinic) or may be more a fundamental limitation on what the biomedical treatment can provide. In either case, medical pluralism and multifaceted decision making about treatments is likely to remain an important feature of the ARV era for the foreseeable future.

Conclusion

Closing reflections

As I left Kebbi at the end of my fieldwork in 2012, taking an early morning motorcycle taxi to the motorpark to catch my bus, I felt heavy, weighed down by mixed feelings and memories. I was sad, of course, to be leaving friends. I was also regretful of the tasks I had been unable to complete – invitations not accepted, documents uncollected, and details missed. I was relieved a little also, to be done with the petty discomforts of life in Kebbi: I no longer needed to stay in a place so hot that drivers tie handkerchiefs around leather steering wheels to avoid burning their fingers.

The most wrenching feeling, however, and one that has troubled me ever since, is a kind of elusive anxiety about the value and purpose of the work that I have done. I had no doubt that I had a privileged and unusual vantage point on this setting and this moment in Nigerian history. I had witnessed events that were both ordinary and remarkable: a man at rock-bottom gambling everything on a new business venture, a couple finding a joy that surprised even themselves, and an officer at an NGO wryly admitting his own powerlessness before resolving to press ahead anyway.

The question that weighed me down was what to do with the things that I had seen. Should I rekindle the practical disposition I prized as a VSO volunteer, and write a thesis thick with instrumental problem solving, filled with suggested good practice for care providers and strategies for NGOs? Should I redouble my treatment access activism, in the hope that some change in the global health architecture might swell the trickle of largess that flows down to places like Kebbi? Or must I search for some new theoretical twist or conceit that would help a wider academic community understand the ARV era?

All of these approaches have appeal and merit. What felt most pressing, however, was how health institutions continued to demonstrate little understanding on the lives of HIV positive people. In policy talk, 'suffering'

was something to be reduced – but with only a shallow appreciation of what that suffering might consist of. Lives would be extended by drugs, programmes, and projects – but extended into what?

Médecins Sans Frontières (MSF) have long been attached to the principle of *témoignage* (witnessing) in the face of suffering.[92] This is a moral act as much as a political one, in that it holds that speaking out about suffering has a value that is not necessarily tied to a remedying of that situation. Something similar can be said in the case of listening to people talk about the things that trouble them, as I tried to do in Chapter Four and elsewhere. Though, as I discuss in Chapter Two, the interpersonal act of listening can have its own unburdening and therapeutic consequences. Providing words and form to previously elusive and inarticulable experiences can help make suffering understandable. Once this has been done, attempts to tame or remedy that suffering can take place from a sure footing.

Suffering and misery are not the only things that demand and require witnessing. There is an intrinsic value, too, in sharing the unexpected possibilities of the ARV era, as people seek and sometimes find great joy in their lives, even if it rarely comes without overcoming severe obstacles. I also take this process of witnessing and the following of lives over time to be of a piece with a now somewhat unfashionable African studies tradition of research that emphasises fine-grained empirical data collection over more theoretical work[93]. This is an approach that seems to best fulfil my commitment and obligation to this group of people, and the institutions that serve them.

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[92] Though as Peter Redfield's (2013: especially 102-111) history of the organisation shows, MSF's own commitment to *témoignage* – initially conceived as a counterpoint to the perceived shortcomings of the neutrality of the Red Cross – has had a complicated and uneven history.
[93] As Paul Nugent (2009:11) notes, this tradition is now most commonly found in doctoral work.

Learning from the ARV era

There are other things to be gained from a close study of HIV positive lives, however, than just this morally necessary act of witnessing. Reflecting on the emerging features of the ARV era is a topic of interest both in and of itself, and to other situations where people live with chronic and stigmatised illnesses. It is also a vantage point for advancing various debates within development and African studies.

As the title of this thesis implies, the most important aspects of the extended lives of the ARV era can be found in a dialectic between intimacy and politics. The empirical chapters of this thesis approach this dialectic in different ways. Chapter Four tries to open up the notion of suffering, rather than relying on pre-ARV era studies of HIV to presume what it is. Doing so makes it possible to explore changes in how people have suffered since the ARV era began. Public health talk about HIV becoming a 'manageable chronic illness' is true in a narrow sense. But this belies the complex issues involved in rebuilding after trauma, coping with a fraught and painful present, and fearing an uncertain future.

It also demonstrates the highly uneven nature of support that is provided to HIV positive people. Support groups have been widely identified as an important resource in dealing with HIV related trauma and treatment issues (e.g. Power *et al*, 2003). But what actually happens inside such groups has only recently begun to be explored (Marsland, 2012; Walstrom *et al*, 2013). It is important, then, to contribute to an understanding of how groups like KAPOP can be fairly successful, but also how they can fail badly. These failures come about because they either do not address the broad nature of suffering (which often includes psychological or mental health dimensions), or because the funding logics of such programmes depend upon maintaining and presenting particular notions of suffering. There will be no straightforward ways to address this in settings where resources for care and support are already stretched so thin. But there may nonetheless be

opportunities to modify interventions so that they better account for complex, intimate forms of suffering[94].

Chapter Five elaborates upon one thread of the suffering chapter; the Nietzschean notion that suffering can be a jumping-off point for renewal and personal betterment. Finding a new relationship is crucial for rebuilding a sense of self-worth in a way that is both public facing and deeply personal. This chapter takes the unusual step of exploring the nature – rather than the mere existence – of post-HIV relationships. These relationships are unique as assemblages of existing social norms and appropriated and modified ideas from elsewhere. Those in these post-HIV relationships are modern lovers, experimental and self-aware, carving out a place for themselves in an often-hostile social order. As unique as their circumstances are, thinking through the choices they make and resources they use is a useful means to extend the burgeoning debate on love, romance, and modernity in Africa (e.g. Hirsch *et al*, 2009; Spronk, 2012).

Chapter Six continues this exploration of innovation and making do in difficult circumstances, in this case, in dealing with economic aspects of living with HIV. Whereas many Nigerians rely on family for both help in building a livelihood and insurance in times of crisis, HIV positive people are often cut off from such support. Securing their treatment and wellbeing, then, requires new strategies. These strategies sometimes focus on solidarity with other HIV positive people, and sometimes rely on rehabilitating or preserving whatever strained family ties remain.

An additional complication – but also source of comfort – is the variety of treatment options offered by different medical traditions. Choosing between this plurality of therapies is again often made easier through alliances with fellow HIV positive people. These questions of treatment seeking and treatment decisions have long been staples of medical sociology and medical

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[94] Some pilot projects and studies have begun to address this question (e.g. Bhana *et al*, 2013; Walstrom *et al*, 2013).

anthropology, and gain renewed urgency in the ARV era, given the permanence of HIV in the body, and the frequent separation from the usual support networks. Even when drugs are available, and programmes exist to supply them to ordinary people, HIV positive people still have other important therapeutic needs, which they must seek out and pay for without support from formal authorities.

Even as the intimate struggles of HIV positive people for wellbeing and dignity go well beyond interactions with state medical services (as described above), they are nonetheless dependent on the reliable provision of treatment. Elsewhere, HIV positive people often use support groups as vehicles for collective political advocacy (especially in South Africa, e.g. Niehaus, 2013). However such models, (typically involving claims on the state) are of little relevance in Kebbi. KAPOP is positioned as a recipient of aid, and not an agitator for change. Additionally, stigma forecloses other common possibilities for representation. Given the political marginalisation of HIV positive people, Chapter Three take a different approach from the other empirical chapters to explore other sets of actors in the ARV era.

Successful advocacy for healthcare is dependent on a specific, locally adapted form of engagement with Kebbi's system of patrimonial governance. I argue that doctors are able to successfully engage the state government as they have both important connections and adopt a sensibility of pragmatic compromise. NGOs, in contrast, are made irrelevant largely through their own making: their needlessly narrow mode of working makes them unable to negotiate with the state on its own terms.

Kebbi and Nigeria have their own distinctive political features, but exploring that context nonetheless contributes to broader debates. In particular, recent discussions about development patrimonialism and working 'with the grain' (e.g. Kelsall, 2008, Crook and Booth, 2011) have raised important questions, but are in need of further empirical elaboration, this study has attempted to provide. Similarly, this chapter contributes to continuing debates on how to

characterise states that combine formal institutions with informal flows of resources and decision-making (e.g. Alemu and Scoones, 2013).

Paths not taken

Given the breadth of both the HIV pandemic and its consequences, any account of the ARV era must be an incomplete one. Indeed, I use the term 'ARV era' to draw attention to the specificity of the historic moment, not to suggest some kind of monolithic shared experience. The themes here have been chosen because they represent particularly salient and exemplary viewpoints on this moment, but they are by no means the only possible themes and perspectives.

Certainly, the ARV era will be realised differently in different places, and studies of others contexts (and comparisons between them) will yield important insights. Thematically, too, many issues were presented to me in the field that I chose not to pursue for various practical, ethical and intellectual reasons.

As I have set out in Chapter Two, for this group of HIV positive people, the clinic or hospital were not normally important places, but rather ones to be visited as rarely and briefly as possible. Nevertheless, important things can happen there, particularly in contexts where medical contact is more substantial and frequent, as interactionist (Watermeyer and Penn, 2013) and ethnographic (Kyakuwa, 2009) studies have demonstrated.

I also say almost nothing about children. The ways in which stigma and dependence on drugs affects both parenthood and childhood are profound, as a small number of studies have begun to explore (MacCarthy *et al,* 2013; Moses and Tomlinson, 2013).

Similarly, both in the field and in the writing of the thesis I found myself judging the families who had rejected their sons and daughters. In my empathy for apparently harshly treated HIV positive people, it is easy to think that those doing the stigmatising or rejecting are ignorant or simply

villainous. But social dramas rarely have such simple characters, and the dynamics of family rejections deserve to be understood from the obverse of the perspective I have provided. I imagine somewhere in Kebbi there is a young man who nods in agreement as his parents complain about the disgrace their daughter has brought to the family, and vows never to contact her again. Only later, perhaps, does he secretly text his sister, promising to send money when he can. His story deserves to be told too.

Faith is central to everyday life in Nigeria, and religious beliefs, understandings, and metaphors recur in the lives of the individuals I have described. I chose not to address the topic as a separate theme here, as it seemed to me when faith was discussed, it was in the context of and as a motivation for framing other practices – be they economic, social, or personal. Others, of course, have considered HIV and religion directly[95].

Pills are essential to the ARV era, but are themselves largely silent in this study. In a literature review prior to my fieldwork, I considered ways of theorising these drugs. Could pills become agents in themselves, enrolling other actors in their projects? Or might those taking these drugs be seen as combinations of humanity and technology, and consider themselves "unwelcome cyborgs of society" (Gagnon, 2009:22; following Haraway, 1985)? If so, there was little to furnish such lines of enquiry in the conversations I had with HIV positive people. In fact – to my dismay – they tended to speak of their pills in remarkably mundane ways. A complicating factor, however, is that HIV positive people tend to be harangued by doctors and others about their medicine. Therefore, when I asked about pill-taking habits, or feeling towards medicine, I felt strongly that I risked adopting a similarly intrusive, patronising, or nagging posture.

The list of other potential topics here continues: I heard barely a mention of sex workers, gay men, or drug users, though they are widely discussed in the

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[95] Useful reviews and new material on this topic can be found in a recent special issue of the Canadian Journal of African Studies – see Burchardt, Patterson, and Rasmussen (2013).

context of HIV in other settings. The oldest HIV positive people I spoke to were in their mid-fifties, but as ARVs extend lives, the topic of HIV and old age will require more attention (Hosegood and Timaeus, 2006).

The ARV era

In spite of the diversity of the topics covered within this thesis, and those outlined above that lie beyond it, there are certain recurring issues and themes that are widespread, probably throughout much of Africa. Most central of all is the importance of family rejection, and its long-lasting and multifaceted consequences. Not everyone in this study experienced this phenomenon (and indeed some benefited from family solidarity), but it was extremely common[96]. If I have laboured this point, it is because for those who experienced such estrangements, almost every aspect of their lives were affected. For them, the ARV era is not quite a post-family era, but it is certainly one in which family relations must be reconfigured or substituted for.

The other main theme that this thesis foregrounds is the capacity of HIV positive people to reinvent and adapt. This capacity is neither universal nor limitless – as the several case studies suggest. The distressing examples of Nafisa and Hadiza (discussed in Chapter Four) suggest that some individuals are trapped in cycles of despair and pain that are difficult to escape.

The HIV positive people in Kebbi are largely powerless in political terms, but in other areas of their lives, they are anything but. Even in less than promising circumstances, HIV positive people can find ways to rehabilitate what has been lost, and build towards better futures. The lives extended by ARVs are often uncertain ones: the continued provision of vital drugs depends on political processes they cannot influence, and their wellbeing relies in large part on coming to terms with deeply personal forms of strife.

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[96] It would be useful for future studies to explore how this phenomena varied between places, and if it was declining over time as part of a putative 'normalisation'.

That so many do find a measure of stability and contentment is a testament to their own resilience at least as much as it is a gift from medical science.

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Appendix

Verbal consent script – English version

I am a student at the University of Edinburgh, in the United Kingdom. I am studying HIV treatment in Northern Nigeria. I am interested in how HIV positive people get the money and medicine they need to be healthy. I am also interested in how HIV changes people's lives.

If you agree to participate in this study, I will ask you questions about your life, and your experience of living with HIV, or looking after people who have HIV. This usually lasts between 30 minutes and 1 hour. Some of these may be personal or sensitive questions. You are free to choose not to answer any question. I will also stop taking notes if you prefer. You are also free to end the conversation at any time. If you decide to stop the conversation, you do not have to give me a reason why.

Anything you tell me will be private. I will not use your name or any details that might identify you when I write and publish my work. I will not tell anyone that we have had a conversation, and I will not reveal your HIV status. My notes will be stored securely.

You will not be paid for taking part in this study, but I will cover your transport costs for getting here today. Helping me with this project will not affect your treatment in anyway.

Do you have any questions about me, my project, or this conversation before we begin?

My supervisor is Dr. Elizabeth Olson (elizabeth.olson@ed.ac.uk). If you have any concerns about this study or my behaviour, you can contact her. If you need help sending her an email, I will help you.

You can contact me at pete.kingsley@gmail.com, 0789 931 706 while I am in Nigeria, or +44 780 6649 188 while I am in the UK.

[give paper with contact information on to participant]

Verbal consent script – Hausa version

Takardar Neman Amincewar ka

Ni dalibi ne daga jami'ar Edinburg wacce take a kasar Turai wato United Kingdom. Ina yin nazarin yadda ake kulawa da kuma bada maganin cutar da aka fi sani da suna HIV a Arewacin kasarnan. Ina kuma da sha'awar sanin yadda mutanen da suka kamu da wannan rashin lafiya suke gudanar da rayuwarsu, misali kamar yadda suke samun kudin magani da samun cikakkiyar kulawa don inganta lafiyarsu da kuma yadda suke gudanar da rayuwarsu ta yau da kullum. Ina kuma son nasan yadda ita wannan cuta ta HIV ta canja rayuwar mara lafiya ta yau da kullum da kuma sauran jama'a gaba daya.
Idan ka amince muyi wannan hira zan tambayeka ne akan rayuwarka ko kuma wanda kake kulawa da shi, da kuma yadda rayuwarka ko kuma rayuwar wanda kake kulawa da shi ta kasance a wannan halin da ka samu kanka ko kuma wanda kake kulawa da shi dauke da wannan kwayar cuta ta HIV.
Hirar ta mu zata dauki kamar minti talatin ko kusan awa daya. Wasu daga cikin tambayoyin da zan yi maka sun shafi rayuwarka ta yau da kullum wasu tambayoyin kuma sun shafi rayuwarka ta sirri. Saboda haka kana da zabin ka amsa duk tambayar da kake ganin ba sirri bace a gareka, ka bar wacce take sirrin ka ce. Kana kuma da damar da zaka dakatar dani ko kuma wannan hirar ba tare da ka bada wani dalili ba

Za'a killace wannan nazarin da zan yi bayan na kamala shi sannan ba zan yi amfani da sunan ka ba ko kuma wata alama da zata tabbatar cewa da kai muka yi wannan hira, sannan kuma ba zan tattauna da wani game da wannan hirar tamu da kai ba, sannan kuma na yi alkawarin ba wanda zai san matsayin da kake ciki wanda ke dauke da wannan cuta ta HIV. Saboda haka hirar ta mu da kai za'a killace ta a matsayin sirri. Bayanin da zan samu daga gareka ta nazari ce kawai wato ba zasu shafi kulawar da kake samu na magani ba sanan kuma ba biyanka zan yi ba amma zan biya ka kudin motar da ka biya wajen zuwan ka nan don bani bayanan da zasu taimaka min wajen nazari na

Idan kana da Karin bayani ko kuma wasu tambayoyi game da wannan tattaunawa da zamuyi kana da ikon ka tambaye ni kafin mu fara. Bayan haka kuma idan kana son kayi tambaya game da ni ko kuma wani abu daya shafi wannan nazari, za ka iya rubutawa malama ta dake jamia'ar mu wasika a adireshi kamar haka;

Dr Elizabeth Olson, University of Edinburgh. Email; elizabeth.olson@ed.ac.uk). Idan kana bukatar taimako wajen rubuta wasika zuwa gare ta zan iya yin hakan sannan kuma zaka iya samu na a wannan adireshi a lokacin da nake nan Nigeria kamar haka; Email; pete.kingsley@gmail.com Lambar waya; 0789931706. Idan kuma na koma Turai (UK) zaka iya samu na a wannan adireshi na kasa. Lambar waya ; +44 780 6649 188. Na gode.

Acronyms

AIDS – Acquired Immune Deficiency Syndrome

ARV/ART – Antiretroviral drugs / Antiretroviral therapy

AZT – Azidothymidine (an early antiretroviral drug)

CBOs – Community Based Organisations

GHAIN - The Global HIV/AIDS Initiative in Nigeria.

Global Fund - The Global Fund to Fight AIDS, Tuberculosis and Malaria

HFA – Health for All (a pseudonym for an organisation I discuss in Chapter Three)

HIV – Human immunodeficiency virus

IDU – Intravenous Drug Use

KAPOP – Kebbi Alliance for Positive People

MSF - Médecins Sans Frontières

MTCT – Mother to Child Transmission [of HIV]

NACA – National Agency for the Control of AIDS

NEPWHAN – Network of People Living With HIV/AIDS in Nigeria

NGOs – Non-Governmental Organisations

PAR – Participatory Action Research

PEPFAR – The President's Plan for Emergency AIDS Relief

SACA – State Agency for the Control of AIDS

VSO – Voluntary Service Overseas

WHO – World Health Organisation.