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Institute of Development Studies

University of Sussex

Thesis Submitted for the degree of Doctor of Philosophy

Changing Understandings of HIV and AIDS through Treatment Interactions

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September 2010

Declaration

I hereby declare that this thesis has not been submitted, either in the same or different form, to this or any other university for a degree.

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Acknowledgements

Institute of Development Studies
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DPhil

Changing Understandings of HIV and AIDS through Treatment Interactions

Summary

The problem of HIV internationally has many wide ranging impacts on people, communities and countries' development. In the last decade antiretroviral (ARV) treatment has emerged as the major scientific-technical solution, albeit a costly one. Access to ARV treatment is of vital importance across Africa and around the world. Resources for HIV treatment, care and support are transferred globally on a massive scale. However, how such programmes operate 'on the ground' in different contexts is still unclear. This research contributes to understanding the experience of the people who access such treatment programmes in different contexts. This research focuses on this gap, exploring how treatment programmes are experienced, how the availability of treatment impacts both on people's experience of being HIV+ and how the availability of treatment may also change perceptions of what it means to be HIV+, both individually and at a societal level.

This research focuses on the lives and experiences, particularly the treatment experiences, of people living with HIV in peri-urban Gambia. Low prevalence countries such as The Gambia can provide a compelling example of the ways in which meanings and understandings of HIV are created. Here, entering a field of health pluralism and fluid knowledge creation around HIV-infection, came large scale actors providing a high-profile ARV treatment programme through clinic-based medicine, and an effective de-pluralisation of the medical field in relation to HIV, inviting scrutiny of how such knowledge relations and differences are experienced. Although not anticipated at the outset of the research, in parallel the Gambia has become the locus of a major, politically-backed, 'alternative' AIDS treatment programme. This has thrown the personal and societal meanings of HIV into a new and sensitive context, compelling research attention into how knowledge, status and meanings around HIV are negotiated, and how people make choices amongst different treatment options.

Contents

List of Abbreviations

AATG – ActionAid The Gambia

ACT-UP – AIDS Coalition to Unleash Power (US)

AIDS – Acquired Immune Deficiency Syndrome

APRC – Allience for Patriotic Reconstruciton and

ANCS – L'Alliance Nationale Contre le Sida (Senegal)

ANT – Actor Network Theory

ARV – Antiretroviral

ART – Antiretroviral treatment

ASK – Allahtentou Support Kafoo

CBO – Community Based Organisation

CSO – Civil Society Organisations

CCF – Christian Children's Fund (Now Childfund)

CCP – Co-ordinated Country Proposal

CCM – Country Co-ordinating Mechanism

CCSI – Community and Civil Society Initiatives

CRS – Catholic Relief Services

DAC – Divisional AIDS Council

DAH – Development Aid for Health

DfID – Department for International Development

ESRC – Economic and Social Research Council

GAMNASS – GAMbian Network of AIDS Support Societies

GAVI – Global Alliance for Vaccines and Immunisation

GF – Global Fund

GFATM – Global Fund for AIDS TB and Malaria

GHI – Global Health Initiatives

GIPA – Greater Involvement of People with AIDS

GUM – Genito-Urinary Medicine

HAART – Highly Active Antiretroviral Treatment

HARRP – HIV/AIDS Rapid Response Programme

HCW – Health Care Worker

HIV – Human Immunodeficiency Virus

HIV+ – HIV positive

HIV- – HIV negative

HIV-1 – Human Immunodeficiency Virus, type 1

HIV-2 – Human Immunodeficiency Virus, type 2

HIV/AIDS – Human Immunodeficiency Virus and/or Acquired immune deficiency
syndrome

HoC – Hands on Care

ICASA – International Conference of HIV/AIDS and Sexually Transmitted Infections
in Africa

IEC – Information, Education and Communication

IGA – Income Generating Activities

IRIS – Immune Reconstitution Inflammatory Syndrome

MAC – Municipal AIDS Council

MAP – Multi-country AIDS Programme

MoH – Ministry of Health

MRC – Medical Research Council

NAC – National AIDS Council

NAS – National AIDS Secretariat

NACP – National AIDS Control Programme

NGO – Non-Governmental Organisation

NIA – National Intelligence Agency

OPD – Out Patient Department

PEPFAR – President's Emergency Plan for AIDS Relief (US)

PLWHA – People Living with HIV or AIDS

PMTCT – Prevention of Mother to Child Transmission

PPTCT – Prevention of Parent to Child Transmission

PR – Principle Recipient (of Global Fund grant)

RVTH – Royal Victoria Teaching Hospital

SR – Sub-Recipient (of Global Fund grant)

STD – Sexually Transmitted Disease

STI – Sexually Transmitted Infection

TAC – Treatment Action Campaign

TASO – The AIDS Support Organization (Uganda)

TB – Tuberculosis

UN – United Nations

UNAIDS – Joint UN programme on HIV and AIDS

UNDP – United Nations Development Programme

VCT – Voluntary Counselling and Testing

WANTRAP – West African Network of Traditional Practitioners

WB – World Bank

WEC – Worldwide Evangelisation for Christ

WHO – World Health Organisation

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Figure 3: Inside Brikama Market

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1.   Introduction

Internationally HIV and AIDS pose a huge problem, with many wide ranging impacts on development. In the last decade antiretroviral (ARV) treatment has emerged as a major scientific-technical solution, albeit a costly one. Access to ARV treatment is a key health issue across Africa and around the world. International initiatives, notably the World Health Organisation's '3 by 5' initiative (set up to provide treatment to 3 million people by 2005) and the Global Fund for HIV, TB and Malaria's (GF) grant system, among other global health initiatives[1] are, while not meeting their ambitious targets, making significant inroads to provide treatment in resource-poor contexts. The GF alone by November 2009 was treating 2.5 million people with ARVs around the world[2]. As the number of people accessing treatment increases[3] so too do national prevalence rates and the number of people living with HIV relying on services provided alongside treatment for support and care[4].

With this vast transfer of resources for HIV treatment globally taking place and attracting research and policy attention, a major research gap remains in understanding the 'on the ground' experience of those people who access these treatment programmes in different contexts. This research focuses on this gap, exploring how treatment programmes are experienced, how the availability of treatment impacts both on people's experience of being HIV+ and how the availability of treatment may also change perceptions of what it means to be HIV+, both individually and at a societal level.

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[1] In the Gambia drug provision is financed by the Global Fund, and has in the past been a recipient of the World Bank's Multi-Country AIDS Program (MAP) – HIV/AIDS Rapid Response Programme (HARRP); elsewhere the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is a major donor as well as other private-philanthropic or NGO run programmes or a mixture of these.

[2] Global Fund http://www.theglobalfund.org/en/fighting/?lang=en accessed December 2009

[3] From 7% in 2003 to 42% in 2008 (UNAIDS 2009; 9)

[4] An increase in people on ARV treatment is associated with a reduced number of deaths, and so an increase in national prevalence rates. However, although recent figures indicate that prevalence is stabilising despite an increase in access to treatment (UNAIDS 2009), treatment also implies a relatively stable community of people accessing services, including but not limited to treatment, over the long-term.

This research focuses on the lives and experiences, particularly the treatment experiences, of a small group of people living with HIV in peri-urban Gambia. Low prevalence countries such as The Gambia provide a compelling example of the ways in which meanings and understandings of HIV are created in different contexts. Entering a field of health pluralism and fluid knowledge creation around HIV-infection, came large scale actors providing a high-profile ARV treatment programme through clinic-based medicine, and an effective de-pluralisation of the medical field in relation to HIV, inviting scrutiny of how such knowledge relations and differences are experienced. Although not anticipated at the outset of the research, in parallel the Gambia has become the locus of a major, politically-backed, 'alternative' AIDS treatment programme. This has thrown the personal and societal meanings of HIV into a new and sensitive context, compelling research attention into how knowledge, status and meanings around HIV are negotiated, and how people make choices amongst different treatment options.

In this context, the analysis picks out some of the issues these people faced in accessing and taking treatment, and in seeking to remain healthy – to make a living and find sufficient food in the face of extreme poverty. These issues encompass at once an immediate concern with their livelihood and that of their family, and also a wider view which takes in the architecture of HIV funding within the Gambia and beyond, and the ways in which this shapes people's options and the ways in which being HIV-positive can become a livelihood, linking into income streams. The decisions people living with HIV make around personal issues – when and to whom to disclose their status, taking medicines, having children, breastfeeding – are all discussed in a vast international literature ranging from the descriptive to the prescriptive. The risks they face in making these choices to their health and their sense of personal security and dignity can be great. The sacrifices people make in 'coming out' and disclosing their status can be worth it in terms of material, social and psychological gains, but they can also backfire and lead to distress and discrimination.

Many of the HIV-related activities which this research explores are recognisable from other studies focusing on similar programmes as ARV treatment has been 'rolled out' around the world (see for example Nguyen et al 2003; 2007; Booth 2004; Hardon

et al 2007; Schumaker and Bond 2008; Alcano 2009; Meinert et al 2009). This study, similarly to these others, looks to describe how what has become a thoroughly global phenomenon, internationally funded ARV drug provision, comes to be grounded, interpreted and negotiated in a particular local context. In The Gambia different centres provide patterns of treatment, care and support some of which are based on 'best practice' from elsewhere, part of a 'Global AIDS' industry which often glosses over the individuality of differently experienced epidemics (Cassidy and Leach 2009b; Edstrom 2008; 2010). Rules and procedures – for example the necessity to disclose in order to start treatment or around VCT and testing – cut a direct line from the global to the local, and very personal. Coupled with these procedures are programmes bringing assumptions around people's lives – their rights and responsibilities – on a broader plane than merely the medical. It is these dynamics, and the way that they have played out that this research aims to describe.

In the rest of this introduction I start by outlining the key issues and gaps in the literature which this thesis addresses. This includes a description of the issues around the ARV treatment programme around which this research was originally designed. The second section briefly outlines the story of my fieldwork. It outlines in broad strokes what was a rapidly changing AIDS treatment landscape during 2006-2007, indicating how events nuanced and required adaptations in my research focus. Key events include those related to the organisation and financing of the treatment programme, the organisation of groups and networks of people living with HIV, and – most strikingly - the development of a presidential 'AIDS cure' programme in 2007. This description moves through different spaces, in which people living with HIV experience, construct and enact their status to greater and lesser extents. The third section describes the way in which these spaces fit together, and can be conceptualised. This discussion serves to provide an overview of the structure of this thesis, and outlines the contents of each of the following chapters.

1.1. ARV Roll-out – emerging issues

The HIV treatment programme in the Gambia was one of the first major programmes to provide free universal treatment for people living with HIV in a low-prevalence

country in West Africa, and is funded by the Global Fund. Currently HIV prevalence in the Gambia is estimated to be around 4% of the adult population[5]. This is in stark contrast to nations in Southern and Eastern Africa where prevalence has in some countries been estimated above 20% (UNAIDS 2008). In studying HIV treatment in a low prevalence country this research encounters specific challenges and opportunities. The dynamics of understandings and meanings of HIV and AIDS are different here than in countries where HIV is more commonly encountered, and recognised among one's friends and neighbours. Here, then, the dynamics of stigma and also support, and the processes through which HIV and AIDS are placed within different frames of understanding can be seen in a context where HIV infection has not reached an overwhelming state of emergency as elsewhere, and is less well studied and understood.

There are many hopes and fears around the provision and scale-up of ARV treatment around the world, particularly in resource poor contexts which face challenges of inadequate infrastructure and staff. One major hope is that treatment will 'normalise' HIV as a chronic and manageable condition, reducing the stigma and fear surrounding infection, and so impact upon treatment seeking behaviour and transmission. Such arguments raise important questions about HIV and identity. As Rohleder and Gibson suggest, the negative connotations of HIV infection - the 'spoiled identities' of HIV-positive people – are internalised and at the same time resisted;

> [people] struggle with these notions of themselves… splitting off these bad representations and projecting them outside of themselves, onto 'others' who were then represented as 'bad'. Most commonly, it is those that have not tested, and thus do not know their statuses, who come to represent the 'bad' deviant 'other'. Another means of defence is to split their experience of themselves into 'bad', sick past self, and a 'good' healthy present self on antiretrovirals. The deviant 'others' becomes those that do not take care of their health.
>
> Rohleder and Gibson 2005; 20

Antiretrovirals in the South African context have been at the centre of very public advocacy campaigns. The identities discussed above fit into these political

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[5] Prevalence rates of 2.8% for HIV-1 and 0.9% for HIV-2 (The Gambia UNGASS Report 2008, http://data.unaids.org/pub/Report/2008/gambia_2008_country_progress_report_en.pdf accessed December 2009)

movements, and the broader publicity that HIV treatment activism mobilises in this context. Robins (2005) suggests that through treatment people are 'reborn'; previously socially dead, they benefit both through regaining their health and also through involvement with organisations such as the Treatment Action Campaign (TAC). Whether and how these experiences are replicated in a low prevalence country, without the broader political and social mobilisation seen in South Africa is unknown, and another area in which this research contributes.

One of the major challenges – and fears – around providing universal access to ARV treatments is the risk of drug resistance, which is amplified where there is suboptimal (e.g. <95%) adherence to treatment (Stevens et al, 2004). It is critical, therefore, to understand the many factors which influence people's behaviour around seeking and taking treatments for HIV. Globally there has been much debate as to the viability of providing ARV treatment in resource poor contexts. The work of Paul Farmer and others both in providing treatment and documenting the viability of these programmes in the early 2000's pushed this debate forward[6]. Recent studies have found that overall adherence in resource-poor contexts is not significantly different from that of patients in resource-rich contexts (see Orrell 2005 for a review). However, there is still some debate as to the viability of providing treatment where the necessary staff and infrastructure to support patients, specifically in adherence, cannot be provided. Meanwhile, studies which focus on adherence outline that many factors can still have huge impacts on adherence for individuals and particular social groups as will be discussed in chapter 2.

People's decisions about their treatment are at once shaped by and shape their understandings of HIV. In the Gambia, as elsewhere, ARV treatment is available in a context in which biomedical and non-biomedical understandings of health and illness interact. In different circumstances individuals, alongside their family members and embedded within their communities, come to treatment decisions for different conditions which may include a range of treatments from herbal or Koranic treatments to clinic-based medicine. Equally some illnesses are seen as amenable to one type of

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[6] See the Harvard Consensus Statement - advocating treatment access for all based on pioneering work in Haiti, where free ARV treatment was first offered by the Partners in Health clinic
http://www.pih.org/library/essays/IntroducingARVs/speech.htm

treatment or another, although once one option is exhausted another may be sought. While ARV treatment is set within a strong knowledge-power base of clinics and funding and is presented as the only option for people living with HIV it is contestable, as this example shows. In the following chapters this theme, of contestation within plural understandings, returns many times, illustrating the complex basis of people's negotiations around these issues.

HIV and AIDS-related stigma is an important factor to consider when looking at treatment provision. Internationally, HIV-related stigma was identified as an issue on which research is a high priority in order to better understand its role in disease control and the impending introduction of systematic ARV delivery. The situation in Botswana, for example, where the rollout of ARVs has been significantly under-subscribed despite estimated 30-40% prevalence rates, is a strong indication that social research to complement drug provision is necessary to enhance effectiveness (COCEPWA 2003; Rollick 2002).

Various technologies, regimes and measures to support adherence have been suggested, in the Gambia as elsewhere, such as alarms to remind patients to take drugs. Locating treatment within patients' lives and considering the ease with which treatment is integrated into routines, as in this study, allows a focus on how such treatment regimes act within patients' social worlds, including experiences or perceptions of stigma – as, for instance, measures publicise the patient's condition to those around them. Levels of understanding of both HIV and AIDS and treatment, as well as levels of real or perceived stigma experienced by participants will have differing effects on different people, depending on questions of gender, age, wealth and other aspects of social position, as well as personal and family circumstances.

In terms of health and coping this study follows people living with HIV as they access and go through treatment, attending to the changes this brings. As people make choices around treatment, support and other services – for instance in negotiating the necessity of disclosure in order to begin treatment, or reflecting on how easily and comfortably they can access the clinics – so a variety of social relations and social spaces are implicated. And dilemmas often arise. For instance in practical terms people have quantities of drugs to store in their homes, and regular drug taking to

explain to families and others, to whom they may not have disclosed their status. The decisions people make as to the limits of their disclosure also impact upon treatment. For example, the eligibility committee in the Gambia has specified that disclosure to a 'buddy'[7] to support them is necessary for those starting treatment. Here again, how different people interpret and negotiate this condition of eligibility, and how and from whom they are able to gain support, are key issues. Addressing them will allow a clearer picture both of some of the wider social factors to be considered in providing ARV treatment, and of the nature of socially-differentiated experiences of it.

1.2. *HIV treatments in the Gambia – outline of events*

Initially three centres in the Gambia started the 'roll out' of antiretroviral treatment (ART, or ARVs) in September 2004. These were, firstly, the HIV clinic at the Royal Victoria Teaching Hospital (RVTH) the main national hospital in the capital, Banjul. Until international funding arrived to pay for space and staff as well as drugs this clinic was not functioning. At the start of the GF funding until early 2006 they used another clinic's space on Fridays and had very few regular patients. The second centre was the Gentio-Urinary Medicine (GUM) clinic at the Medical Research Council (MRC) Laboratories in Fajara, an international research centre which offers treatment primarily to those enrolled in research studies. In the case of HIV infection all those testing positive were entitled to remain attached to the clinic, and research participation was optional; this involved monitoring as part of the HIV cohort, as well as participation in specific research projects. In early 2004 this clinic had a few patients on dual ART[8] already under a research project, and provided care for about 1500 other patients with HIV-1 or HIV-2 infection some of whom would have benefited from ARV treatment. Thirdly, roll-out was co-ordinated by Hands on Care (HoC), in Brikama, a large town approximately 40km from the main urban areas, and the capital of Gambia's Western Division. This is an independent clinic set within the grounds of the government health centre. This clinic operated as a Community Based Organisation (CBO) during the research period and now has NGO status. HoC was set up and run by a Christian missionary organisation, WEC (Worldwide Evangelisation

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[7] A treatment 'buddy' is an individual, usually a friend or family member, to whom the person beginning treatment discloses their HIV-status, and who then supports the person beginning treatment through this process, reminding them to take their drugs regularly and also acting as a support person .

[8] Triple therapy is now standard, but at the time these patients enrolled in the study in the previous century that was not the case.

for Christ), and then partially funded by them as well as other religious organisations. This shift occurred gradually, but management was already devolved from close affiliation by 2006. The change in status is in large part a reaction to insecure funding streams and the greater independence this gives for fundraising. As treatment started in the Gambia HoC, similarly to MRC, had some patients ready and waiting to start treatment.

These three centres acted as three of the main sub-recipients of the Gambia's Global Fund Grant for the treatment and medical care of people with HIV. They were also a major focus of my research; places where I carried out participant observation, took part in meetings and trainings and interviewed staff throughout the research period. I also used these centres to reach those people living with HIV who were not members of support groups.

Patterns of both support and resource allocation through Global Fund-NGO income streams centred on Support Societies for people living with HIV. Within the study area there were initially two groups: *Santa Yalla* (Praise God) and *Nganyia Killing* (One Heart); attached to the MRC and HoC clinics respectively. *Santa Yalla* was the first to be formed, with the introduction of the first members to each other facilitated by clinic staff, a pattern which was then followed at the other clinics. These first two groups had the institutional and financial advantage of having been included in the proposals and work plans for both the HARRP[9] and Global Fund Grants, so giving them more security. As my fieldwork started differences between members and clinic staff in Brikama (HoC) forced a split, with many members of *Nganyia Killing* forming a new group, *Allah Tentou Support Kafoo*, ASK (Thanks be to God Support Society[10]), and both groups continued in Brikama. Throughout my fieldwork period there were active patients at RVTH who, with the facilitation of counsellors, met

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[9] HIV/AIDS Rapid Response Programme – World Bank Funding through MAP (Multi-Country AIDS Programme) in the first round, which acted as 'seed money' for the Global Fund (GF) grant, for both drug provision and other activities. By being in existence when these plans were made these groups were more secure in terms of rent and utilities. They were also named as part of the stress on the inclusion of civil society within GF structures.

[10] *Kafoos* are groups usually formed along gender and age lines which form a major part of social organisation in the Gambia. Often linked to groups formed at initiation and remaining as mutual saving and cooperative societies throughout people's lives, more recently they also function as membership associations for shared contributory saving and social welfare activities.

sporadically at the clinic. This group, *Lilahi* (Praise God) gained strength and momentum throughout my time in the Gambia, but only managed to secure their own office/drop in centre at the end of 2007 (with UN funding).

Through this period the structures for people living with HIV in the Gambia changed significantly. Groups upcountry (in the regional main towns) started to gain momentum as the clinics there developed and ART was scaled up through 2006. A national network, GAMNASS and a national network for women, Mutapola, were started. These processes also became an important focus of my research, which came to encompass taking part in meetings and following the key individuals. The nascent networks were sites of expression for people to discuss their priorities and put these forward, and also of contestation as different people and different ideas competed for dominance.

Through 2006 another important research focus became the provision of resources and income streams available through these structures. For people living with HIV, and particularly support society members, the provision of material support was a major concern, often discussed. Through 2004 and 2005 programmes involving the support societies had built up under the HARRP programme. By 2006 people were well aware of the HARRP and GF programmes, and their shortcomings were often discussed in group meetings and in general conversation. Expectations had been raised as to what could be available for people living with HIV – and there was a keen awareness of the volume of money in the country 'for us'. However, support group members perceived a gulf between their own material day-to-day priorities and the priorities of those organisations implementing these global programmes in the Gambia. Common perceptions included the widespread belief that those in positions of power within NAS and elsewhere 'ate the money' and looked after themselves, while people living with HIV struggled. The funding situation in the Gambia is discussed in more detail in Chapter three, but suffice to say here that by the end of 2006 the financial situation was precarious. The HARRP funding ended and while existing GF programmes were running, including treatment, a new grant proposal had been refused. At this time people within the groups who had salaries found their positions – as cleaners, cooks and so on – cancelled. The nutrition programmes, providing food daily in the groups, were also cut as well as other benefits. Group

members looked to other means to support themselves and attendance at the centres dropped as people devoted their time to trading and other occupations.

In early 2007 the landscape of HIV treatment in the Gambia changed again, this time more suddenly and dramatically. On January 18th the recently re-elected president, Yahya Jammeh, announced his 'mandate' to cure AIDS (and Asthma)[11]. It has never been made explicit from whom the mandate has come, although supportive commentators have called it a 'gift from Allah'. The AIDS remedy consisted of 'seven herbs named in the Koran', to be administered to patients through bodily washes and a drink, administered by the president himself through procedures bound with secrecy and intricate rules:

> I can treat asthma and HIV/Aids and the cure is a day's treatment. Within three days the person should be tested again and I can tell you that he/she will be negative….. I will not treat anybody who is not diagnosed as asthmatic or a HIV/Aids patient by a doctor. I don't want to give my medicine to a wrong person…. I am not doing it for money or popularity. The mandate I have is that HIV/Aids cases can be treated on Thursdays. That is the good news and the bad news is that I cannot treat more than ten patients every Thursday. There is nothing I can do about it and if I go beyond that I will have to pay the price[12].

On the morning following this announcement nine people, including one woman with a young child, all members of the main three support groups in the Gambia – *Santa Yalla*, *Ngangia Killing* and *Allah Tentou* – rushed to the statehouse to take part in the president's 'programme' as requested. Of these nine, four were taking antiretroviral drugs under the Government-Global Fund treatment programme. From the statehouse they were moved directly to Serekunda Hospital, a newly built and as yet unused hospital designed to serve the main urban area and replace the existing and inadequate health centre. They were the only residents here. Shortly afterwards, a further 27 people were recruited for treatment. An additional 38 were recruited on 17th April, and a further 32 - including several foreigners from Senegal, Guinea Bissau and other

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[11] Since this time he has made further claims to breakthroughs in curing hypertension, infertility and tuberculosis.

[12] http://www.statehouse.gm/pres-rvth-board_170107.htm

neighbouring countries - on 9th August[13]. These people were kept in a hospital with no medical staff - 'Jammeh is our nurse'; driven daily to the Statehouse for treatment, and periodically taken to Kanilai, the president's home village, where he planned to open an AIDS treatment centre. The other people with them were predominantly security personnel. All patients under the president's programme were required to cease ARV treatment, on the grounds that this would interfere with the herbal/Koranic cure.

Laboratory testing in Senegal - and subsequently in Morocco among other 'secret' locations - has purported to show that the treatment 'worked', as stated in repeated claims in the president's speeches, in media publicity and on his Statehouse website. However dubious the interpretations of viral load and CD4 counts used to make these claims, the president has discharged a number of patients as 'cured', most notably in a major ceremony on 31st July 2007 when the first and second batches of patients were released. In the ensuing period, many of these so-called cured people became ill and several died.

While in some respects an extension of the 'traditional' AIDS treatment that had previously been available in the therapeutically-plural Gambian context, Jammeh's 'cure' programme was distinct in its scale, power and presidential authority. By 2007, then, people living with HIV were negotiating their understandings of the disease and treatment options amidst two powerful, yet contrasting, programmes – the biomedical GF-funded ARV roll-out, and the president's 'traditional' programme. In the organisation of this thesis I seek to avoid a contrast between a 'before and after' depiction of pre (2006) and post (2007) the introduction of the presidential programme. Although there are contrasts and differences to be raised between these two periods there are also continuities and similarities. These raise issues about the experience of being HIV+ in this contested arena of expertise and legitimacy around the treatment of HIV.

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[13] A further group was registered at the end of the 2007. Many people in clinics feel that these are people who had previously been 'lost' to treatment – testing positive but not attending clinics or not 'accepting' their diagnosis - who came forward with the hope of a cure. It is not, however, possible to verify these opinions.

1.3.   Spaces – outline of chapters

> For us, the human body defines, by natural right, the space of origin and
> distribution of disease: a space whose lines, surfaces, and routes are laid down,
> in accordance with a familiar geometry, by the anatomical atlas. But this order
> of the solid, visible body is only one way – in all likelihood neither the first
> nor the most fundamental – in which one spatializes disease. There have been,
> and will be, others.
>
> <div align="right">Foucault 1963 (2003); 1</div>

Being HIV+ is a difficult and traumatic aspect of oneself to come to terms with. HIV
is a virus, but to carry this virus rather than millions of others carries with it multiple
meanings which extend far beyond medical diagnosis and the 'familiar geometry' of
the body, and impact on all areas of life. The spaces which are examined in the
following chapters and through which I have chosen to organise the exploration of
treatment interactions in this thesis make up the main arenas of people's lives: their
bodily and experienced life; their domestic or community life; their engagements with
treatment spaces in clinics or otherwise, and the support societies. There are of course
other spaces which people move through – where they work or study, or where they
socialise outside the home or support group. However, the spaces I focus on contain
the majority of settings and activities – in which the disease is 'spatialized' in the
social world. They also contain the major dilemmas and decisions people face around
being HIV+.

Chapter 3, Global Spaces, is an exception, dealing with issues which are not and
cannot be experienced in one place. This is the chapter in which I explore key
elements of the global AIDS industry: its assumptions, architectures and funding
flows, as well as the institutions through which these have been manifested in The
Gambia. What emerges here as 'Global AIDS' is best understood as a discourse or
assemblage (Ong and Collier 2005) which is also experienced through each of the
more emplaced spaces described in the following chapters. Through an HIV+ test, a
clinic visit, or a workshop, or through disclosures counselled towards or enforced to
gain access to drugs, people experience the global. Global discourses framing HIV
also shape experiences of being HIV+; sometimes individualising the body in taking
and adhering to drugs, sometimes socialising the HIV+ body within a global sphere of
activism and understandings.

Spaces are not bounded entities independent of each other, and within and between each of the following chapters, different spaces overlap and intersect. There are aspects of the global within people's imaginings of themselves and the virus in their blood, just as there are aspects of the domestic and local space within the clinic, and so on. Nevertheless looking at spaces, attending to these porous and fluid constructions of HIV, and meanings of being HIV+ in different spaces can add up to a richer sense of the experience of living with the virus. And it reveals how for people living with HIV every situation requires a balancing act of disclosure and secrecy, of benefit and risk, and of belief or performance.

Running through each of the ethnographic chapters are three major themes; understandings of science and its construction, the partiality and positioned nature of the construction of different knowledges and their legitimacy and justification (Jasanoff 2004; Latour 2005; Collins and Evans 2002; Fassin and Fassin 1986). This leads into debates around controversies and how people choose to engage, or disengage with issues and causes, including the role of different publics in the delineating the boundaries of science and non-science on controversial subjects (Foucault 1994; Leach and Fairhead 2007; Fassin 2007; Agrawal 1995; Natrass 2008; Epstein 1996). Following this, is a focus on HIV and its social context. This includes discussion of social support and HIV-related stigma and discrimination (Farmer 1992; 2000; 2004; Castro and Farmer 2005; Sontag 1991; Bond 2005; Parker and Aggleton 2003), and adherence to treatment regimen. There is a vast literature on factors shaping adherence (Jani, 2002; Daar et al, 2003; Murphy et al, 2000; Lucas et al, 1999; Chesney et al, 2000; Arnsten et al, 2002; Hill et al 2003; Adam et al 2003; Alcano 2009), demonstrating the importance of acknowledging the many dimensions involved, and specifically ARVs in resource poor contexts (Sow and Desclaux 2002; Coetzee et al 2004; Orrell 2005; Harries et al 2004; Mugyenyi 2004).

Chapter 2 outlines the theoretical framework which informed and shaped this research, elaborating on these themes. First, it addresses knowledge, concepts and belief systems, around understandings of HIV, AIDS and treatment, and related ideas – systems of the body, blood and immunity and differing conceptions of these, informed by medical anthropology (Heald 2002; Leach and Fairhead 2005; Bledsoe

2002; Martin 1994; Geissler et al 2008). Secondly, it grounds the individual and interactive focus of the thesis, thinking of how the individual navigates institutions and adheres to treatment regimen, with insights from social psychology and 'actor-oriented' approaches (Long 1992). Thirdly, it elaborates on the relational focus of the thesis; on social context, the networks and relations between people and the social 'fields' (Bourdieu 1984) in which they are constrained and at the same time construct, drawing on Giddens' (1984) theory of structuration. This chapter also focuses on the methodology, the methods used and the issues faced in carrying out the research.

Within this framework chapters 4 to 7 attend, respectively to: the bodily space and the physical experience of being HIV+; the domestic space and the social experience of being HIV+ in this space in the specific context of peri-urban Gambia; treatment space, focusing on the clinical spaces within which people learn of their HIV status and form long-lasting relationships as they continue in treatment, as well as the challenges to this posed by the president's treatment; and finally the support groups as spaces in which being HIV+ is a given, spaces in which new identities are formed, often in opposition to behaviours in the home.

In conclusion, chapter 8 pulls together these themes and asks what lessons can be learnt from these spaces: in terms of policy and practice around the provision of treatment and other services for people with HIV; and in terms of the implications for the 'global' of the local understandings exposed here - both the treatment controversy which the Gambian president's challenge to international authority brings, but also the smaller scale disaffections and negotiations faced by people living with HIV.

Throughout this analysis it is important to stress that people's overriding response to the ARV treatment programme in the Gambia was positive. A sense of ownership, belonging and gratitude often shone through. While there are many criticisms to be made and difficulties to be overcome, the impact that ARVs have on people's lives is undeniable. This is why it is important to chart the realities of these programmes, as this thesis attempts to do.

2. Understanding HIV treatment interactions: theoretical and methodological themes

This research began as a study of how people living with HIV in peri-urban settings in The Gambia engaged with the biomedical ART programme being rolled out here during the mid 2000s. In the course of the research, as the last chapter described, the president's own high-profile treatment programme, based on a very different set of non-biomedical precepts, came into play. This shift of context sharpened the relevance of the two major themes which underpinned the concerns of the research from the beginning: first, how treatment interactions are shaped by and shape people's knowledge, concepts and beliefs about HIV and therapy; and second, how treatment decisions and engagements are shaped by people's interpersonal and social relations. However, the president's 'breakthrough' and claims about it also pitched the study's concerns with bodily and therapeutic understandings into a wider context of controversy about biomedicine versus non-biomedicine, science versus non-science, and the politics of these distinctions. At the same time, it became clear that people's 'micro' engagements with these various forms of treatment sit within larger sets of social, political and institutional relationships that extend up to the global level. Subsequent chapters, tracking through global, clinic, support society, domestic and bodily spaces, highlight the ways that knowledge and social-interactional dimensions of treatment become negotiated within and between these different 'levels'. This chapter contextualises this multi-space ethnography, by introducing the two major themes, concepts and underlying literatures that have informed it, and then discussing the methods used to investigate these within different spaces.

2.1. Knowledge and science around HIV and treatment

The first major theme that has informed the study concerns knowledge, concepts and belief systems around understandings of HIV, AIDS and treatment. Introducing this here leads into a broader discussion of understandings of science and its construction, the partiality and positioned nature of the construction of different knowledges and their legitimacy and justification, and of controversies and how people choose to engage, or disengage with issues and causes.

2.1.1. Understandings of HIV, bodies and treatment

Illness throughout history has both physical manifestations and layers of social meaning and discursive construction in social life.

> Any disease that is treated as a mystery and acutely feared will be felt to be morally, if not literally contagious… Contact with someone afflicted with a disease regarded a mysterious malevolency inevitably feels like a trespass; worse, like the violation of a taboo.
>
> Sontag 1991 [1978]; 5-6

HIV, like other diseases and conditions before, is wrapped in meanings and metaphor which entangle together with the physical signs and symptoms to become a social entity of itself. As we enter the fourth decade in confronting the challenges of HIV and AIDS around the world these conditions are woven into a web of meanings and taboos – linking blood, sex and death – which colour the way we look at HIV infection, the way it is dealt with in policy and in practice. Edstrom (2008) charts these changes through different stages:

- viral transmission , behaviour and primary prevention in the late 80s and 90s, to;
- disease progression, management and treatment from the late 90s to mid 00s and to;
- impact mitigation and what to do with those affected – esp. children – from the beginning of the millennium to the present.

These changes in the way the epidemic is imagined and discursively created affect ideas as of what 'should' be done, and also who is affected. These interacted over time with the biomedical and political-economic realities of treatment availability and effectiveness in different contexts, and the emergence of international structures and campaigns. Edstrom also asks how such depictions of HIV and AIDS, and the international actions which they generate, are "co-construct[ed] narratives … often using the issue as a convenient peg for broader concerns" (2008; 2). This issue is discussed in greater detail in the following chapter – 'Global Spaces'.

The images of who is and is not affected by HIV and AIDS are deep rooted – no one wants to believe that 'it could be me'. Cooper and Forster (2008) illustrate in their study of well-educated youth in South Africa, working in the field of HIV, that even this 'atypical' group distance themselves from the epidemic through their language.

Images of the epidemic as rooted in Haiti (Farmer 1992) and then Africa (Patton 2002) further illustrate this 'othering' on an international scale.

From the 1980s organisations such as ACT UP and others in Europe and America, mainly linked to gay rights activism, and later with grassroots organisations globally such as TASO in Uganda and the TAC in South Africa, have been instrumental in challenging some of the constructions of what HIV is and who gets it. However, early epidemiological discussion of 'risk groups' – gay men and injecting drug-users in Europe and America, and more widely 'prostitutes' and the promiscuous, have led to both the widespread tendency to disassociate from the possibility of HIV-infection for oneself and one's peers, and also to a process of stigmatisation as HIV infection takes on various moral meanings. African women's choices – or lack of choices – were often presented in an undifferentiated construction of sex workers (Standing 1992). While discussion has moved on in many areas, Goffman's (1963) ideas of 'spoiled identities' still hold true in many situations where silence and denial remain the norm.

Susan Sontag's work on the metaphors we inevitably use to talk about health and illness, and the often counterproductive frames this gives us to discuss bodily and social dis-ease, makes a powerful argument against discussing HIV and AIDS in terms of 'war' - a metaphor which is often used, which she states should be 'retired'. Similarly she critiques discussion of 'victims' – and the inevitable adjudication of innocence and guilt this brings – or of HIV as "plague-like, a moral judgement on society" (1991; 147).

 Here, the importance of the construction of models for understanding HIV and AIDS, our metaphors and the programmes and projects they justify are brought into question.

> The AIDS epidemic serves as an ideal projection for First World political paranoia. Not only is the so-called AIDS virus the quintessential invader from the Third world. It can stand for any mythical menace.
> Sontag 1991; 149

What can be seen in many examples of AIDS programming – both in treatment and prevention – are the imposition of 'western' interventions, with medical models taking precedence over local understandings (Allen and Heald 2004; Heald 2002;

Heald 2003). Alternatively, in returning to constructions of 'risk groups', mandatory testing and enforcement, AIDS is positioned as a security issue, to which an emergency response is required (de Waal 2003; 2004; 2010; Poku and Whiteside 2004; Putzel 2004; Prins 2004).

Looking at these changing models and metaphors, opens questions of what interventions are appropriate to different contexts, and how to make such judgements. For example, the necessity of pre- and post-test counselling for HIV testing is universally accepted as beneficial to the acceptance and understanding of diagnosis. However, the reality of what 'counselling' consists of in completely different social and cultural contexts, particularly in settings with scarce resources for health services, is little understood.

This thesis explores how different understandings and discourses about HIV – including those derived from external and biomedical models, and those linked to people's own understandings, as revealed through anthropological research – intersect. Here the interlocking of these sometimes contradictory, sometimes reinforcing frames can illuminate both different interpretations of the issues and options, and the ways in which such travelling discourses have 'grounded' in the Gambia; being enacted, reinterpreted and negotiated at different sites and through different relationships.

2.1.2. Understandings of the body

As many works on medical anthropology have demonstrated, understandings of disease are co-constructed with particular understandings of the body (Good 1994; Kleinmann 1978, 1997; Kleinman et al 2006; Scheper Hughes and Lock 1986; Csordas 2002; Lambert and McDonald 2009). In biomedical understandings of HIV infection and transmission, bodily fluids harbour the virus, and it acts on the immune system, breaking down the body's defences. However as Suzette Heald has similarly questioned in Botswana (2002), how well these categories translate in particular African settings is open to question. In relation to HIV in West African settings, local constructions and metaphors of blood are of particular relevance to understandings of the disease.

Fortier (2001) outlines the different systems of 'white blood' and 'red blood' and their different functions within the body elsewhere in the West African context. Here, the red system of blood is female, linked to menstrual blood, the formation of the foetus in the womb and fleshiness. The 'white' system is masculine, where sperm is part of a circulatory system of fluid residing in the spine, which breathes life into the 'red' system of blood in conception, and is related to breastmilk (2001; 109-110).

In East Africa 'red' blood is the "principle substance of relatedness, including kinship, and of life, growth and continuity" (Geissler 2005; 21), however this does not appear to be the case in West Africa (Fortier 2001). In the Gambia in discussion of the system of white fluid "the physiology of relatedness emerges", where, for example, shared wet nursing creates bonds of kinship which prohibit marriage (Leach and Fairhead 2005; 7). 'Red' blood in this context "is associated with the liver, the organ of the self and of emotion" (ibid; 8). Red blood is important for strength, both in pregnancy and for work "the stuff of life – the vital force of living things… linked to plumpness… a physical sign of a person 'doing well'" (ibid). As such, blood is lost and gained, conserved and spent through different daily activities, as well as through the bodily functions of reproduction.

> Blood can be lost, but it is replaceable only with great difficulty, and the time frame in which repletion can occur is much slower… The best way to replace blood is transfusions in hospitals. Because blood is so difficult to replace, however, blood donated to one person is considered to be lost to someone else. Even close relatives donate to one another with great reluctance.
>
> Bledsoe 2002; 174-175

In the Gambia "through donation practices blood has evidently become a commodity, and a valuable one at that" (Leach and Fairhead 2005; 8). Through examining idioms of 'blood stealing' by MRC medical researchers, the ways in which people construct exchanges involving blood, and interfaces with medical science and research, can be examined (see also Geissler et al 2008). Interpretations of blood taken as part of medical trials include blood 'stealing', which can be dangerous especially in the case of children; and of a kind of 'transaction' where the MRC repay people for their blood through services. The selection criteria are also worrying for people involved in trials, which plays into "speculation about the qualities of African blood and of the trans-

national economy of blood" where the 'strength' of 'good' African blood was seen as a possible reason why the MRC would go to such lengths to collect it. (ibid; 11)

When blood is taken, several different ideas of where it goes are presented; as resistance to wider concepts of post-colonial control and globalised power 'debating the merits of modernity' (Geissler 2005; see also Geissler et al 2008). Blood is rumoured to be sold for use by 'whites' either as blood with 'strength', or transformed into medicines (Leach and Fairhead 2005), again linking aetiologies of the body to wider systems and constructions of power and control.

Here the different layers of discourses and knowledges are linked together in ways which potentially subvert messages about HIV and AIDS. As in Botswana, for example, public health messages around condom use interacting with, or in contradiction with local understandings of bodily fluids (Heald 2002) or, in Zambia, understandings of colour based in traditional medicine influencing ARV use (Schumaker and Bond 2009). Such understandings influence people's opinions and decisions as to how best to act, or to follow their treatment, in order to maximise their options and chances. This may mean tapping into more than one seemingly contradictory explanation simultaneously, and to unexpected results based on differing rationalisations of the situation and options available.

As Schepher-Hughes and Lock (1987) describe the bodily experience is inextricably linked, created and imagined, through three fields: the body as lived; the body-social; and the body-politic. This model has been criticised for objectifying the body and neglecting the bodily foundation of culture; "If embodiment is an existential condition in which the body is the subjective source or intersubjective ground of experience, then studies under the rubric of embodiment are not "about" the body per se. Instead they are about culture and experience insofar as these can be understood from the standpoint of bodily being-in-the-world" (Csordas 1999:143). However, in this linked-bodies model, bodily experience, "the body's importance in self-experience and self's experience of the others" (McGuire 1990; 285) is linked to the formation of identities, an important theme in this thesis. Thus understandings of blood, of HIV and of treatment spread through these three fields, gathering meanings for those experiencing and enacting this condition.

As medical anthropology has shown, and as described further below, local understandings are context-specific, often plural, socially-varied, and can lie at odds with dominant western science. These issues and the particular ways in which they shape understanding and action around HIV and its treatment in The Gambia, are taken up, in particular, in chapter four – 'Bodily Spaces'.

2.1.3. Understandings of therapy

The focus of this research is an interest in people's diverse understandings of HIV and treatment, and how this shifted through treatment interactions. In the Gambian context as elsewhere plural health systems operate side-by-side. As chapter four on Bodily Spaces explores in detail, people combine and move between biomedical, herbal, 'traditional' and Islamic frames and therapeutic systems. While from some perspectives these sometimes seem contradictory and incompatible, for those navigating such plural systems, they present an operable and non-contradictory landscape.

Many studies in various settings discuss the plural nature of health systems and health seeking behaviour within these frames, based on many different factors (Baer 1995; Bledsoe and Goubaud 1986; Fassin and Fassin 1986; Janzen, 1978; Leach et al 2008; Obermeyer 2000; Scheid, 2002).

Simultaneously international structures and programmes which define and address health problems often seek to impose biomedical understandings, and encourage take-up of biomedical treatments. The following chapter – Global Spaces – outlines the trajectory of such discourses with specific reference to HIV and AIDS, and in how this plays out in the Gambia. As others have described for various disease focused programmes as well as other global health interventions such as vaccinations, global programming often seeks to 'de-pluralise' therapeutic options, presenting the particular biomedical solutions on offer as the only way. Yet in practice, plural therapy-seeking often persists (Leach and Fairhead 2007; Yahya 2007).

Thus plural and de-pluralised, biomedical understandings of therapy coexist and compete. They intersect; nowhere is the project of de-pluralisation complete.

Throughout this thesis, in the different spaces represented by each of the following chapters, elements of biomedical and other therapeutic framings recur and interact in different ways in people's treatment-seeking around HIV and AIDS.

2.1.4. Science, politics and treatment controversies

The previous section discussed diverse ways of knowing – which is a definition of science in its broadest sense. However more narrowly, science can be defined as formalised bodies of knowledge generated and affirmed through evidence obtained through specific types of method and practice.

Within some views, science is objective and value free, and biomedical science – with which mainstream understandings of AIDS and ART are interlocked – is often portrayed this way. However, the social construction of science literature reminds us that this is not the case.

> The sociology of science rests on the postulate that the objective truth of the product - even in the case of that very particular product, scientific truth - lies in a particular type of social conditions of production, or, more precisely, in a determinate state of the structure and functioning of the scientific field. The 'pure' universe of even the 'purest' science is a social field like any other, with its distribution of power and its monopolies, its struggles and strategies, interests and profits, but it is a field in which all these invariants take on specific forms.
>
> Bordieau 1975; 19

Science is a contested field, with many players and interests competing for dominance and legitimacy. Medicine is also a plural field with different systems existing side by side in different contexts. Some of these exist within the heuristically defined definitions of 'science', others without. HIV, as discussed above, is a social phenomenon. It is also a scientifically defined virus, although this too is the cause of much controversy and debate in certain quarters. A brief consideration of the construction of scientific knowledge is important here as this sheds important light on the ways in which different knowledge systems gain authority and control, and how contestations play out. In the Gambian context contestation and debate over the authority of different kinds of knowledge has been central to everyday HIV treatment interactions. However this became heightened as the president's treatment programme

came into play, with controversy and legitimation struggles between 'science' and 'non-science' coming to the fore.

Science, and its role as a field of constructed knowledge, is built upon recognisable methods and legitimacy based on verifiable facts. However, science is not a technical, neutral exercise. Instead scientific 'truths', claims and methods are always co-produced with particular institutional, social and political commitments (Latour and Woolgar 1986; Jasanoff 2004). Further, the co-production of natural-scientific and social order often pulls science into a nexus of legitimation, defining the 'natural', or conversely the 'unnatural' (Jasanoff 2004).

Feminist critiques of science illustrate how all knowledge is positioned and partial (see for example Haraway 1985; 1991; Wajcman 1995; 2009). As Harraway describes, the bases of such knowledge delineate identities from certain standpoints:

> In the traditions of 'Western' science and politics--the tradition of racist, male-dominant capitalism; the tradition of progress; the tradition of the appropriation of nature as resource for the productions of culture; the tradition of reproduction of the self from the reflections of the other - the relation between organism and machine has been a border war. The stakes in the border war have been the territories of production, reproduction, and imagination.
>
> Haraway 1991; 150

Within such a masculinised, western frame, the experiences of HIV+ women are logically constructed in particular ways: as the subjects of technical interventions, and as infectious agents to 'save' their children without concern for their survival[14]. The process of disclosure can also be highly gendered: in order to access ARVs women

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[14] Neviropene became established through studies is Uganda and Thailand as an efficient and cost effective way of reducing vertical transmission of HIV infection (Lallemant et al 2004; Guay et al 1999; Johnson et al 2005). However, although significant reductions in new infections were an important breakthrough the effects of this treatment in drug resistance for the mothers and those children who did become HIV-infected were also significant (Arrivé et al 2007; Wind-Rotolo et al 1999; Eshleman and Jackson 2002; Eshleman et al 2004). Since this time more work has been done to find treatment regimen which both address the problem of vertical transmission, and also caters for the future treatment of the mothers and infected children (Brocklehurst and Volmink 2002; McIntyre et al 2009). In most contexts internationally single dose neviropene remains the main method of prevention of mother to child transmission.

are enactors of technological medicine, within the male domain of medicine and clinical space.

From a constructivist perspective, the spectrum of understandings through 'western science' and 'local knowledge' can be understood as positioned and partial, representing biases inherent within a given community. As with understandings of HIV as outlined above, constructions of particular issues are produced in tandem with other preoccupations, fears and policies in the wider social and political context (see for example; Edstrom 2010; Dry 2008; deWaal 2010). As Knorr Cetina puts it, "There are, for constructionism, no initial undissimulatable "facts": neither the domination of workers by capitalists, nor scientific objectivity, nor reality itself" (1995; 147-8).

The production of scientific (or local) knowledge can also be understood in terms of actors and networks (Latour and Woolgar 1986). Actor Network Theory (ANT) imbues not only actors but also actants (objects) with power to shape spaces and relationships. While this study does not follow an ANT approach in its entirety, ANT insights into the power of actants prove are helpful in highlighting the roles of ARVs – for instance in shaping clinical space and relationships (chapter six – treatment spaces). In this sense, the thesis explores the life of a particular technology – ARVs - in society, and the situations in which they are given meaning and legitimacy, based both on understandings of their chemical properties and the organisations, institutions and relationships in which they appear. Such networks stretch from the medical to the political and the social, taking in patients, clinics and clinicians as dispensers and pharmaceutical producers. Equally the Global Fund, governments, local agents, NGO staff and counsellors all relate to each other in associations which produce and reproduce the 'truth' of ARVs, how they function and how best to bring them to people. ARVs, within these networks, arguably express the same level of agency as patients, doctors or nurses. As medicines these are experienced as chemical and as social things, but the very individual and embodied experiences of side-effects and recovery are mediated by social understandings. People perform being HIV+, their treatment, and 'good' treatment behaviour in different spaces, as they also take and physically experience their treatment.

As each of the subsequent chapters will show, knowledge and 'science' about HIV and treatment in The Gambia is produced and negotiated in different ways through different spaces. In some spaces and contexts – particularly those relating to the presidential 'cure' - such negotiation extends to the very definition of science, and non-science, and the ways in which that which is defined as science is formed and its boundaries defined, assailed, defended and reformed (Gieryn 1983). HIV and the science around its definition and treatment are fertile ground for such controversy, as the situation in South Africa attests (Fassin 2007; Fassin and Schneider 2003; Richey 2008; Nattrass 2008).

Understanding both science and local knowledge as socially constructed in turn raises different questions about the relationship between scientific expertise and that of wider publics (Collins and Evans 2002), as well as about the interface of science and politics – recognising the politicisation of science and the "scientization of politics" through mutually produced 'facts' (Epstein 1996; see also Gieryn 1983; Richey 2008; Natrass 2008). Collins and Evans (2002) discuss the role of publics and the ways in which 'science' has been recognised as no longer just the privilege of a core expert group, but as visible to, validated by and engaged with by other publics. In a normative argument about public engagement with science, they describe three 'waves' in science studies: from an acceptance of privileged scientific expertise (in which publics were often constructed as ignorant); to a second wave of the inclusion of lay expertise and the privileging of publics. In the third wave, they suggest, it is time to assess where such lay expertise is legitimate. Recent literature has seen lay people and patients as experts, with experiential expertise. Activism around HIV has seen people living with HIV become such experts, accepted and expected in discussion of treatment and care (Brashers et al 2002; Ford et al 2009; Robins 2004; 2006). In so doing, they perform particular kinds of citizenship in relation to science and health (Cassidy and Leach 2010; Leach et al 2005; Epstein 1996; Nguyen 2005). In this Collins and Evans (2002) have been challenged as their analysis lay expertise is 'legitimised' by reference to the tenets of science; there is thus little scope to validate and appreciate people's knowledge grounded in other belief systems (Leach et al 2005; Caplan 2000).

This study builds on this literature, and examines the expertise of patients and patients' groups in Gambia. Here I also build on ideas of the patient-as-expert, to explore people's everyday experiences and particular bodily and social understandings as sources of expertise. Moreover, this thesis shows that relevant expertise often extends beyond the technical to the procedural, as people learn not only how to take treatment and adhere, but also how to access funding streams and 'play the game' of international funding. In this context, as elsewhere, they negotiate social and political meanings, and negotiate claims in relation to institutions. There are also limits to this scientific citizenship in relation to powerful global institutions, limits which are both explicit and hidden (Rose and Novas 2005; Cassidy and Leach 2009b). In the Gambian context this became further complicated through the emergence of two parallel treatment programmes; the presidential and biomedical.

In addressing the 'treatment controversy' unleashed by the president's treatment programme, helpful comparisons can be made with other recent studies of controversies over public issues involving science (see for example; Feldman-Savelsberg et al 2000; Poltorak et al 2005; Yahya 2007). Some of these have pitted citizens against scientists, others have played out between different coalitions of scientific and policy actors. Thus Epstein (1996) tracks the ways in which engagement around HIV in San Francisoco in the early 1990s was scientific engagement, and yet distinctly political. In the field of HIV and activism the role of 'expert' widened considerably such that the legitimacy of people living with HIV to participate in discussion became unquestioned, both as experiential experts, and also as an educated and informed public interested in the practice of 'good' science. Engagement around HIV and AIDS has, he says, "resulted in a multiplication of successful pathways to the establishment of credibility and diversification of the personnel beyond the highly credentialed" (1996; 4). The following chapters raise questions around these issues, but in the Gambia in the 2000s what similar elements can be seen of this analysis of the US in the 1990s? Also, to what extent are the knowledge and expertise of people living with HIV really so listened to - and on whose terms?

Science as a shifting and contested field is both defended and assailed. The question raised by Collins and Evans (2002), and which this research also addresses, is how

such claims to expertise and legitimacy are made – on what basis and using which strategies – and how they are maintained. There are many examples of such activism and citizen engagement; ACTUP in the US, TASO in Uganda and TAC in South Africa (Epstein 1996; Grebe 2009). The structures of the GF which require the direct involvement of people living with the diseases they combat further illustrates the openness – at least in theory – of powerful structures involving science to the involvement of publics. However, engagements in science are not always welcome. Many controversies have arisen around HIV, AIDS and treatment in South Africa, again revealing the politicisation of science and the 'scientisation of politics' where the boundaries between who is legitimate in the discussion and who is not are contested and blurred (Fassin 2007; Richey 2008; Natrass 2008).

As these social science literatures have shown, such controversies often involve clashes between different groups of actors who frame an issue in different ways. Different actors or interest groups might draw on 'science' but of different kinds; for instance clinical vs. epidemiological; biomedical vs. Islamic. Contests may then ensue over legitimacy – what counts as 'real' science or treatment, and over credibility – whose science is supported by what evidence (Fassin and Fassin 1986; Fassin 2007; Cassidy and Leach 2009a). These questions are all evident in the Gambian case as the following chapters show.

However, social science analyses of controversies around issues involving science have tended to focus on the controversies themselves and their protagonists. They have paid less attention to how 'ordinary people' continue to negotiate their lives amidst the uncertainties generated by controversies. This is the main focus of this study; what sense people living with HIV made of the unfolding contestation between the biomedical treatment programme and the president's, and how the existence of these debates fed back to shape people's understandings of their own HIV and treatment experiences. At the same time, people's behaviour and decisions in relation to HIV and treatment are shaped not just by knowledge, but also by social processes and interactions, the second major theme of this research.

2.2. *Social processes and treatment interactions*

The second major theme which has informed this research, and which again runs through all the spaces explored in subsequent chapters, sees people's engagements with HIV and its treatment as social processes. As the large literature on HIV and its social context has explored, social processes and interactions are relevant to many dimensions and stages of people's treatment experiences, including of ARVs in resource poor contexts (Sow and Desclaux 2002; Coetzee et al 2004; Orrell et al 2003; Orrell 2005; Harries et al 2004; Mugyenyi 2004). Thus there has been exploration of social factors involved in people's decisions about treatment; discussion of social support and HIV-related stigma and discrimination (Farmer 1992; 2000; 2004; Castro and Farmer 2005; Sontag 1991; Bond 2005; Parker and Aggleton 2003), and analysis of the social shaping of adherence to treatment regimen (Jani, 2002; Daar et al, 2003; Murphy et al, 2000; Lucas et al, 1999; Chesney et al, 2000; Arnsten et al, 2002; Hardon et al 2007). Thus social processes are relevant across a range of issues and decisions, shaping people's experiences as they come to terms with their diagnosis and manage their treatment.

Across these literatures, often implicitly, are a range of different theoretical assumptions and approaches. My approach here combines an individual and actor-oriented approach (Long 2000), with attention to how people operate and negotiate within wider social networks and fields (Giddens 1984; Bourdieu 1985). As I go on to show in the third part of this section, both social action and social fields need to be understood in their particular context of the Gambia, drawing on insights from the anthropological literature from the Gambia and the West African region.

2.2.1. Individualist and actor-oriented approaches

As an individual negotiates different institutional and social settings to access treatment and gain support, an 'actor-oriented' approach enables a focus on people's 'interfaces' with different institutions, individuals and situations, and on how they come to decisions and frame these in different circumstances.

> The issue is how actors struggle to give meaning to their experiences through an array of representations, images, cognitive understandings and emotional responses. Though the repertoire of 'sense-making' filters and antennae will

vary considerably, such processes are to a degree framed by 'shared' cultural perceptions, which are subject to reconstitution or transformation… An actor analysis must therefore address itself to the intricacies and dynamics of relations between differing life-worlds and to processes of cultural construction… grounded methodologically in the detailed study of everyday life, in which actors seek to grapple cognitively and organisationally with the problematic situations they face.

<div align="right">Long 2000; 190</div>

Many models from social psychology try to describe the decisions and actions made in adherence or non-adherence. These are related to several factors, some practical, others relational; setting out the decision making process, paying attention to relationships between intentions, and actions (Abraham 2003). Intentions are also negotiated into action through a series of other factors; perceived control, anticipated regret, preparatory actions and implementation of these, and perceived relevance to self (Fishbein and Adzen 1975; Ajzen and Madden 1986). Such models focus usefully on individual motivations and place an individual's efforts – for example patterns used as reminders to take drugs – within a wider frame, although they simplify the effects of societal or peer opinions and actions on these.

Talcott Parson's work from the 1950s (1951) develops the concept of sick roles; the social expectations of what behaviours, sanctions and allowances are suitable for those deemed to be sick, and the willingness of 'sick' individuals to take on such roles to various degrees, with attendant disadvantages and benefits. A kind of socially sanctioned 'deviance', the sick role, coupled with physical symptoms and side-effects of medications, affects a person's ability to perform social functions within the family or community. Where the sick role inspires sympathy and assistance this may bring benefits, and relieve the individual of responsibilities. However, this diminished position may have negative effects on self-esteem where customary roles – as mother, father, and so on – are eclipsed by the 'sick' identity. This process can work in a reinforcing, progressive or regressive manner. Where factors influencing the 'sick role' are cultural or social, some fixed, others flexible, this potentially gives changing sick roles to conform to within differing socially accepted patterns, or a static sick role to act within or against. This process is necessarily dynamic; people's multiple roles and subjectivities are impacted to different degrees, as roles are accepted or rejected differently in different spaces.

Actor-oriented approaches can also give insight into HIV-related stigma, widely recognised to present a major challenge in the day-to-day lives of those affected, and also as a wider public health issue with regard to treatment and prevention efforts. Thus Goffman (1963) gives an outline of the social formation of stigma characteristics, based on the duality of 'normal' and 'spoiled identities'; a problem of relationships, related to a person's social networks, coping mechanisms and ability to function in society. Thus HIV-related stigma is intricately linked to a person's actions and interaction with their family and community, and their negotiations of identity within these arenas. Rankin et al. set out some of the myriad ways in which HIV-related stigma impacts upon people's lives in the African context, paying attention to the gendered dimensions of the epidemic, how language constructs social categories, how stigma can "devastate a family's chances of economic survival" (2005; 2) and how it is related to treatment and care.

Stigma is not confined to the negative attitudes of others, and the discrimination coming from this. It is also an internalised understanding by people living with HIV of the negative images of HIV, and the fear of negative reactions from others (Alubo et al 2002; Awusabo-Asare 1995; Lee et al 2002). This 'self-stigma' is just as powerful as experienced stigma or discrimination, preventing people from moving in spaces where they feel they could be identified as HIV positive. This can be linked back to the concept of 'sick roles', the acceptability of the sick role associated with HIV or AIDS in society, and the acceptance or denial of this role by the individual. Here I explore how people experience such fears within the different spaces represented by each of the following chapters.

In the research process, in order to engage in a dialogue with people about their lives, it is also necessary to situate 'stigma' within social relations and networks of support as well as of negative and devaluing attributes or situations.

There are many advantages in giving weight to people's thought and agency as they strive to make decisions around their health and treatment, but it also important to situate this within the broader structures of society which shape individual agency and understandings.

2.2.2. Social fields and networks

Drawing on theories of structuration, my research approach has aimed to locate treatment in people's lives by linking their actions and decisions to the relations and fields within which they live, and negotiate. As Giddens has suggested:

> All processes of the structuration (production and reproduction) of systems of social interaction involve three elements: the communication of meaning, the exercise of power, and the evaluation and judgement of conduct.
>
> Giddens cf. Bryant and Jary 1991; 8

All these elements – negotiations of meaning, power and (moral) judgement – are evident in the ways in which people interact with wider societal groupings and networks. By focusing on the social networks and structures which can support or undermine people, by which they are constrained and which they at once create, we are able to see how an HIV+ diagnosis can move within these fields to disrupt or form relationships.

People living with HIV move within and between different spaces; social spaces constructed by sets of discourses, ranging from those about 'Global AIDS', to clinical management of HIV, local understandings of health and healing, and domestic and family expectations. Each kind of space involves different sorts of social interaction, which are both made available by the space and in turn shape it, through a complex process of negotiation.

Theories of social networks give useful frames and concepts through which to approach the webs of relations in a person's life. While some of these speak to a quantitative methodology, differing from the perspective taken in this research, these concepts provide constructive starting points for considering the issues which arise when trying to trace or map social interactions.

There are diverse strands of social network analysis. The shift away from structural approaches allowed a freedom to place individual agency and constantly changing and shifting relationships within a wider structure, and to move away from analysis that privileges stability (Scott 1991; Mitchell 1974). Combining ideas based on power

inequalities in exchange and reciprocity with frames from network analysis shows how actors, although constrained by social structure, also have the potential to actively shape it.

Much network analysis is topographical, seeking to map out the 'density' and 'range' of a network (Bossevain 1979; 392). Yet looking at these factors can be reductive, counting the number of individuals a person interacts with, or statistical comparison of different links and networks (Emirbayer and Goodwin 1994).

Other strands of social network analysis, more helpful to my approach, have instead focused on the roles and functions of networks. These include maintaining social cohesion, sanction and control, in which the role of networks can be linked to concepts of role and norm enforcement in structuralist thinking. They also include communication, where networks shape "the transfer of information between individuals, the establishment of social norms and the creation of a degree of consensus" (Scott 1991; 31) and the power relations inherent in this. The flow of information through networks can be seen to function in the "connection of gossip with the maintenance of the unity of groups and their morality" (Gluckman 1963; 308). The management of information within networks is important to safeguard one's own position within the group, to reinforce existing hierarchies and to punish transgression. Communication of ideas and information is also a function of networks, with studies of abortionists in America (Lee cf. Mitchell 1974; 292) and contraceptives in Kenya (Behrman et al. 2002) alike showing how people actively seek sympathetic 'network partners', similar to themselves, to gain information from or share information with those they feel will have sympathy or shared experiences. Similarly the choice of people to confide in can be based on 'invisible' features, for example trust between individuals, or "those who keep it a secret, not the talkative ones" (ibid; 717).

Reciprocity is also a feature and role social networks. As Mauss (2002 [1954]) illustrated, being able to return the 'gift' is an important part of maintaining social relations; be this in economic or symbolic terms or in emotional support. 'Unsymmetrical' relationships cannot be maintained, and moreover, the sense of 'shame' and social inadequacy which results in being on an unequal footing with

exchange partners can be disempowering. (Lourenço-Lindell 2002; 173-174). This can be linked to the 'sick role' (Parsons 1951), which may permit a certain degree of tolerance on the part of those giving support, although in chronic or terminal cases where reciprocation is impossible this may act as a disincentive to providing care and support (Bond 2005). Even where there are strong links – kinship ties and loyalties – where resources are scarce the negotiation of "dependence versus disengagement" (Lourenço-Lindell 2002; 214), on both sides, may become necessary.

As medical anthropologists have shown, illness is not a private or individual matter, but a shared concern. The community plays a role in health decision making, with pluralistic concepts both of the treatment options for individual in times of sickness, and the role of the community and 'lay' knowledge in treatment and care (Kleinman 1980; Janzen 1978). In some contexts, particularly where resources are scarce, networks may function inadequately to support individuals in times of need:

> The social network offers help only sporadically, and very often the sick person has to ask friends and family several times before s/he receives assistance. This is particularly true concerning financial support. In times of economic hardship… the variety of therapeutic options is great but come at a high expense, limiting access to desired treatments.
>
> (Bossart 2002; 356)

Different kinds of assistance may be required: economic, emotional support, or practical care. Different people may be called on for different kinds of aid, friends for advice, family for financial assistance, and so on (Schweizer et al. 1998). Accepted norms as to who can be relied upon for different needs, reflect and illustrate wider societal attitudes and beliefs. Definitions of help or support are also subjective; those giving help may not consider it as such but rather as a normal part of their role. Equally, appropriate levels of both support and expected repayment can differ between those giving and receiving (ibid; 42-43).

Focusing on the interactional rather than topographical or functional aspects of networks, Bourdieu's concept of social 'fields' and forms of capital positions actors within different fields according to their relative status, or accumulation of different

forms of capital. In activating a network, or accessing help or support, one can be seen to draw on this capital;

> The profits which accrue from membership in a group are the basis of the solidarity which makes them possible. This does not mean they are pursued as such…
> The existence of a network of connections is not a natural given, constituted once and for all by an initial act of institution... It is the product of an endless effort at institution…which is necessary in order to produce and reproduce lasting, useful relationships that can secure material or symbolic profits.
>
> (Bourdieu 1985; 249)

Where health – the health system or health seeking in a more general sense – is included in this scheme, different individuals have access to different kinds of capital, through their position and in relation to others. As Meinert puts it in her study of Uganda:

> Health – or a good life – is one of the benefits agents strive for in everyday life in Kwapa. Families' quest for what they define as health does not constitute a single autonomous field in the strict Bourdieuan sense. In their quest for health, people attempt to access a range of fields, including the fields of professional health care, healers and herbalists, school, power and religion. Nevertheless, conceptualizing lay health practices as a field helps us to think relationally and see a structured system of social positions that relate to each other in terms of power and resources that are at stake within the field.
>
> 2004; 12

While "the games (*illusio*) of different fields are never fair" (ibid) and people cannot control the 'rules', they can strive to amass and deploy their resources effectively. Here it is possible that positive relations in a network of prestige, would allow greater access to resources or facilities (for example access to treatment) as well as greater support, conversely a 'spoiled identity' linked to the flow of negative or stigmatising information, and illness constraining the ability to reciprocate, would put an individual at a disadvantage in the 'game of health' (ibid).

Meinert further develops this idea to include the body as "also a form of capital which might be added to Bourdieu's theory... Human beings are embodied differently from birth, and… the body is worked upon like other forms of capital…This reflects the pervasive analytical problem in medical anthropology about the body as lived, social

and political" (ibid; 12-13). Her example illustrates the relevance of this conception for this study;

> An HIV-positive friend recounted how The Aids Support Organization advised their members to 'live positively with the virus'. He explained: 'When the body is already weak you must be careful not to stress it more. You try to avoid problems and worries, make sure you stay well with people and plan for your money and future. Otherwise that stress can get you down'. In other words, he was saying that HIV-positive people had low bodily capitals, in the sense that their immune systems could not counteract sickness well. In this situation economic capital (for buying food and medicine) and social capital (for care and emotional support) were considered important to convert into bodily capital and protect the fragile bodily resources of an HIV-positive person.
>
> (ibid; 20)

Over time networks are reshaped, and the additional factor of HIV-infection may change this process. For instance Shelley et al. focus on the 'active' networks of people living with HIV, finding that they have smaller personal networks, although the reasons for this are not clear.

> Some HIV+ individuals told us explicitly that they reduced their interaction with unsupportive people and perhaps individuals who were going to die soon… Another was trying to protect his family and friends by distancing himself.
>
> 1995; 200

Here information known about and by various others is ranked, including HIV-status, and the control of information seems to have some effect on "the much lower average of 'important' people…among HIV+ informants" (ibid) as "those who say they limit knowledge of their HIV status also limit other information about themselves" (ibid; 210). One factor which is not discussed is the role of support groups or collective organisation among people living with HIV, and the potential for mutual support in newly formed networks. Ntombi's study of collective funeral funds in Botswana illustrates how women's collective saving shields families from the shame of being unable to host a funeral and provide for guests:

> It is one thing to experience loss and yet another to weep in poverty, alone. The experience is perceived as akin to standing "stark naked in public" for

everyone to see. There are two dilemmas here. The first has to do with the importance attached to having people provide moral support to the bereaved. The other has to do with the harsh realities of poverty vis-à-vis the social expectation to feed these people.

(2004; 9)

Here, in a different context, the management of social expectations and relationships crosses from the emotional to the economic. In these circumstances the reformation of networks with a specific purpose guards those in need from 'standing naked in public'.

2.2.3. Social relations and interactions in the Gambia

The particular forms that social networks and relationships take in the Gambia reflect particular local and regional contexts and histories. In the following section I outline some of the key themes from ethnographies of the West African region, and some key elements of political and social groupings which characterise West African social worlds, specifically those of Mande-speaking peoples in The Gambia and its neighbouring regions.   In this ethnographic context networks operate on many different levels and the brief outline here provides a basis for more detailed discussion in subsequent chapters.

All ethnography is written through certain theoretical lenses. For instance Bledsoe (2002) takes an actor-oriented perspective, where individuals strategically act to amass wealth and resources. Here, there is less attention to social beliefs and conceptual frames which shape agency. Conrad (1995), on the other hand, presents a more structural view. These combined perspectives provide valuable insights into the different social networks and relationships which can be seen in this context.

Ethnically the Gambia is very diverse, with a wide variety of different linguistic and ethnic groups living within its borders. In this the Gambia's population have much in common with surrounding Senegal, and other West African nations. The majority, around 45% of the population, are Mandinka. Other groups include Wolof, Fula, Jola, and Serahuli, among others. However, sharp distinctions between these ethnicities may not be appropriate, as there is some movement between identities, and historically waves of migration and intermarriage (Wright 2004; 74). This is

particularly the case taking into account political associations. From colonial times Wolof became a dominant group politically, and so the main language of administration alongside English, making Wolof ethnicity a politically and linguistically 'elite' identity. However, Mandinka are the majority in the country as a whole, and in many areas the dominant group. Further tension has been introduced to these identities since the coup in 1994, the current president being Jola. This group, as one of a minority of non-Muslim groups in West Africa, have previously had some negative stereotypes attached to them – as, for example, the traditional producers of palm wine in a Muslim country. Yet the ascendancy of Jola regions in recent years through the patronage of the president has shifted the balance of power and social relations between different groups.

Islam is an organising factor in social and political relations across the whole of the region. The major religion in West Africa, around 95% of the population are Muslim. Through the seventeenth and eighteenth centuries a gradual assimilation of Islamic and local beliefs occurred.

> …lone mystics and scholarly clerics, consumed by spiritual affairs and thus no threat to rulers of states or heads of armies among whom they travelled. These individuals or lineage groups studied the Qur'an… moved about; settled enclave like villages; set up informal schools; sold their ability to divine the future, protect persons from harm and heal bodily ills
>
> Ibid; 98

Today, religious leaders are important and influential figures, leading the community and providing moral guidance on many issues. Mosques are important social as well as religious meeting places, and Islamic schooling is commonplace in addition to state schools. Norms of behaviour for men and women, and culturally sanctioned behaviours, draw their legitimacy from Islamic law. From family structure and initiation ceremonies and practices, to healing and traditional religions, there is a cross-over and blending between the centuries of Islamic influence and various other influences and trends. For example *griots*, traditional oral historians and powerful religious figures, use the Koran in healing, the written words hidden inside leather pouches. Thus it is difficult to separate one system of beliefs from another or to see them as contradictory, but perhaps more useful to see them working together for

people who may be more or less devout Muslims, but may also take on aspects of other belief systems in particular circumstances. Here there are links to systems of knowledge and beliefs, and practices related to these – about the body, healing, purity and impurity – which are played out in these spheres.

> Mandinka communities are structured around families, and the relative power relations between them, based both on access to land and prestige in terms of patronage relationships and relationship to the founding lineage of the village. First occupation of a territory legitimizes the firstcomers and their descendants as 'landowners' who allocate land to later arrivals and have special claims to their allegiance. At the same time marriage and kinship ties between firstcomer and latecomer groups also structure their relations… kinship and territory [have] many overlapping meanings and could be used interchangeably.
>
> Murphy and Bledsoe 1989; 123

In a community the political affiliations around founding families and others who have amassed wealth, power and influence are played out in tensions over village leadership and other political struggles (Beckerleg 1993; 47). The founding family's legitimacy is based upon histories in which "the legendary elements explain past history in encapsulated form and provide the families bases for social identity and claims to political supremacy" (ibid; 49). Strangers moving into the region attach themselves to these lineages, maintaining structure, while adding layers of duality in the distinctions between insiders and outsiders (Ferme 2001; 2).

Further social stratification can be seen in the 'caste' system in which "the rules of precedence are complicated by the existence of the Mandinka three tiered system of social stratification into freeborn, craftspeople, including blacksmiths, and slaves" (Beckerleg 1993; 49). Each of these groups plays different roles, creating a symbiotic set of relationships and functions, particularly around rituals and ceremonial actions, rather than a strictly hierarchical set of allegiances.

> It was the *nyamakalaw* [professional class of artists and craftspeople] who in the past were the principle spokespersons for Mande rulers and chiefs, serving as political advisors and spiritual guides to the noble classes. They continue to act as mediators in Mande society, called upon to negotiate marriages and settle family disputes. While on the one hand acknowledged for the role they play in forming and maintaining the social, political and economic fabric of

the Mande world, the *nyamakalaw* are, on the other hand, presented in the literature as decidedly lower-class citizens….

The colonial construction of the Mande 'caste' system… [is unable] to account for the ambiguity and contradictions of *nyamakalaw* status and identity

Conrad and Frank 1995; 1-2

In this interwoven system, everyone is either a patron, or a client, or both, in different circumstances. For some the adoption of 'stranger' status and attachment to a wealthy and powerful patron is a sound strategy to accumulate wealth and gain protection and security.

There are several reasons why people cannot remain without patrons. In traditional West Africa, those who lack the protection of a powerful patron are vulnerable on many fronts: they may be denied access to farmland or women, or fined on fabricated charges, and in former times they or their families might be pawned or sold into slavery to repay debts, or even killed… no one in traditional Africa is 'free' in the sense of owing no obligation. Everyone is indebted to others to a greater or lesser extent… every adult is a patron to lesser people, but a client to a more powerful person.

Bledsoe 1980; 55

Social organisation is around polygamous patrilinial and patrilocal family groups where the norm is for a man to have up to three wives, conditional on his ability to pay brideprice to the family and to support his dependants (Bledsoe 1980). For a young man to marry may be prohibitively expensive. Also for political reasons certain families may wish to form bonds of marriage. For these reasons a man's first marriage may often be arranged, and the gifts and brideprice be provided by his father, or another patron.

Kinsmen and their families are organised in sections or *kabilolu* (sin *kabilo*) which are conceived of as political and ritual units, and ideally geographical entities, which also carry connotations of clanship – although marriage within the *kabilo* is permitted. Strangers settling into villages are adopted into a *kabilo*, thus preserving the pattern of social relations. Each *kabilo* has both a male and a female head.

Beckerleg 1993; 47

Households 'nest' within a structure of "hierarchies within hierarchies" (Murphy and Bledsoe 1989; 126), down to the level of compounds, where a man and his wife or wives and their children live. Each wife is head of her own unit comprising herself and her children, and in a society where children are highly valued a woman's status, and security, rests on her fertility (Bledsoe 2002).

Kafoos, age-peer groups, act as a unit in many situations – working and farming together (Carney and Watts 1990). These groups are gender segregated and are made up of the age-set who go through initiation ceremonies together, forming a bond of unity within the established system of loyalties to established hierarchies within the community. Secrecy and control of ritual knowledge act here to set up structures of patronage and dependence, within and between men's and women's secret societies (Ferme 2001).

Interlinked and working together, these different forms of organisation can be seen to underpin the social networks within which people go through the stages of their lives, marry, have children, make a living and attempt to amass benefits. While these structures form a framework within which people live, and which influence their behaviour, it is also important to consider the ways in which these different systems are operated by individuals; stretched and negotiated for personal gain, enforced and strengthened by those who benefit directly from them and subverted by those who otherwise may be exploited.

These ethnographies focus, on the whole, on rural areas in the Gambia. Applied to the rapidly urbanising peri-urban fringe they do not take into account of the effects of population mixing, and the impacts of changing livelihoods and living conditions. Some of these structures are being challenged or modified in the modern, peri-urban context of this research. While these remain as an ideal, and are not replaced, these precepts are now overlain with new kinds of relations. Landlord-tenant relationships can be cast as stranger-client, but are also more monetarised and de-personalised; with tenants moving between different compounds and little relationship visible with absent landlords. Also, new kinds of networks are emerging linked to education, new occupations, particularly with NGOs, and crucially with the diaspora (networks that extend across countries, or between Africa and Europe). However, norms around

kinship family and households remain to a large degree, as will be described in more detail in chapters four and five – bodily spaces and domestic spaces.

Also relevant to people's lives in The Gambia are spaces constructed through global institutions (chapter three) and medical or HIV-related institutions, such as treatment spaces and support groups (chapters six and seven). As described above the multiple meanings around HIV shape people's experience, as does their experience of institutions such as clinics and support groups. Yet even these institutions and discourses are shaped by their particular, Gambian social contexts. The porous nature of the clinical space, for example, is very much within Gambian norms of family, ethnicity, gender and relatedness, although superimposed upon this are further norms around medical hierarchies and biomedical expectations.

2.3. Methods - Spaces

Here I outline my methodological approach as applied to the theoretical interests described above. Through this ethnography I used in-depth interactions to understand knowledge and social interactions around HIV within these spaces.

In this research I moved through various spaces – those in which people had disclosed or not, those in which they identified as HIV+, or in which they used such an identity to gain material advantage. Similarly community spaces where there may or may not have been people living with HIV[15]. Through my fieldwork the idea of spaces came to the fore; of social space which is structured by broader issues and institutions, and which individuals also carve out for themselves, which shapes their experience and which is shaped by it.

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[15] In one household which I visited socially a young couple and their new baby lived with their extended family. This family were not interviewed and did not take part in the research. However, my observations of the feeding practices used by this mother indicated to me that she may be HIV+. Her grandmother asked me if this was how *toubabs* (white people) fed their children (exclusive breast feeding for 6 months). Although I do not know the HIV status of any of these people, this was a telling example of the ways in which an HIV+ diagnosis may be made visible depending on knowledge such as this – a theme taken in up in following chapters. It also indicated that many people – such as this grandmother – would have no idea that a close family member is HIV+.

As well as through my research in clinics and support groups, in living with a family I also gained an insight into Gambian daily life; the experience of living in a compound, of shared mealtimes and shared expectations, of gossip and sometimes of censure. This experience also heightened my understanding of moving between different spaces; of forming them myself through the information I disclosed and of being shaped – my research, time and capability – by the pressures and constraints as well as opportunities available in different spaces, as I interacted with institutions and individuals.

My positionality throughout my research was very much 'with' the support groups. My engagement with these people, their concerns and their daily lives has strongly shaped this thesis. These groups were used to outsiders: volunteers, NGO staff and others regularly attended the centres. As such my status as a *toubab*[16] and as a woman was less important here than elsewhere. As described below such differences, and the assumptions behind them are never removed, but the length of time I spent attending these groups mitigated against the potential negatives, as, sadly, did my continued attendance when many of the group members were afraid to come to the centres in early 2007.

I also spent a great deal of time in the clinics, with the staff and the patients there. My various institutional connections are described in greater detail below; however, my relationship with the Medical Research Council (MRC) unit was of most importance. My relationship with the MRC was enabling, in many practical ways, but also created issues around my identity as 'MRC'. The MRC represents many things; foreign biomedical power in conducting research as well as its importance as an employer and providing some health services, including as one of the centres for ARV treatment (see also Geissler et al 2008). While I strove to disassociate myself with this institution, to do so totally proved impossible in many situations.

2.3.1. Fieldwork

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[16] White person

Several issues impacted upon the practice of fieldwork, and deviations from planned activities, which are described here. My fieldwork began in Spring 2006 and was planned for 18 months, until Autumn 2007. However, events around the president's 'cure' programme meant that I returned to the UK for three months from April-June 2007, and continued fieldwork until January 2008. A detailed timeline showing the methods I used tallied to relevant events in the Gambia is included as Annex 1.

I made one preliminary visit to the Gambia in September 2004, after securing funding for the project[17]. This two-week visit was arranged by my medical supervisor then resident in the Gambia and working at the Medical Research Council (MRC) laboratories as the head of the Viral Diseases Programme. This visit allowed me to meet with staff from the three clinics operating at this time and members of the two support groups – *Santa Yalla* and *Nganyia Killing*. I was also able to meet with various people within government and NGOs working on HIV. The aims of this trip were to inform people about the research aims and questions, and also to gain feedback which fed into the research planning. I also gained good background knowledge of the treatment programme, the structures both planned and in-place at this time, and also some of the concerns of support group members. This background information helped me enormously, as I went into the MSc year of my studentship looking at research methods and planning my fieldwork.

My fieldwork included an initial six-month period of language learning. Of the various languages used in the Gambia Mandinka is the most widely spoken – approximately 40% of the population speaking Mandinka as a first language, and a larger proportion as a second or third language. Although I managed to achieve a basic fluency in Mandinka which allowed me to communicate with people and follow conversations and meetings in this language the many other local languages also in common use posed a frustrating problem. Within the clinics and two of the four support groups Mandinka was in use but often secondarily to Wollof. Other local languages in common use were Jola, Fula and, to some extent, Aku. Due to the multi-lingual situation in meetings this issue was eased as translation occurred between the participants already – often also into English for foreigners from other countries in the

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[17] 1+3 Joint ESRC-MRC Studentship

region. Certain group members also took the time to translate for me; all of the men and many of the women spoke English to some extent, or encouraged others to speak Mandinka when I was there. I was aware that when people wished to speak without being overheard they could easily switch to another language – something I was sometimes acutely and frustratingly aware of when observing in the groups and the clinics. My initial slow progress in learning Mandinka was frustrating, and hindered my ability to observe and participate in the groups especially. However, people in this context are accustomed to changing language to accommodate others or to translating for each other so these problems with participant observation were not insurmountable.

In the initial period of my research I also started to engage with the treatment programme and the support groups. I visited the clinics and group centres regularly. At this time I began participant observation at these sites, and built relationships with people in these spaces. One problem which I encountered at this time was the feeling that I was spread too thin – people in all clinics and groups all commented that 'we haven't seen you for so long' even when it had been only a few days. This was exacerbated as the research progressed and more sites developed – two additional support societies as well as the networks. There was also pressure to stay at home – I lived within three different family compounds during my research – and to take part in the life of the compound. My use of public transport to travel between different sites also made the research more difficult in this respect. On the other hand it was important as a levelling factor; had I driven – or been driven – I would have highlighted further the unequal relations between myself and the participants. This also helped me to understand the extreme difficulty of getting things done in this context, the delays, frustration and discomfort of not having access to transport which I shared.

I was never able to resolve the issue of 'not being there' successfully and wished many times that I had a narrower focus, or one geographically located site. As the treatment programme scaled up across the country I was also aware that I was no longer looking at the national treatment programme, which would have been impossible. The balance between 'being there' with each support group and clinic and a need to cover the wider societal issues was a difficult one. However, the length of

fieldwork, as well as my initial visit, played positively into this as although I could not be everywhere every day I became a regular and long term visitor, and gradually an accepted participant in day to day activities and discussions at each of these sites.

In carrying out this qualitative research I used a combination of several methods. Participant observation was used in a variety of locations: the HIV clinics; support groups; meetings, trainings and other HIV related events, some public some private; offices of NGOs and government; as well as people's homes and community environments, including my own experiences of living within a family compound. This approach informed the structure of the thesis – moving between different spaces and observing the different degrees of disclosure, comfort and discomfort and difficulty for people living with HIV in these different spaces, defined and shaped by social expectations as well as institutions and individuals, as is described in the following section.

I carried out individual interviews with approximately 80 people living with HIV in 2006[18]. These were semi-structured interviews looking at their experience of being HIV+, including questions about their health and life before testing, the experience of testing, and their experience since. For those already taking ARVs there was also a discussion of the effects of the drugs on their health, including side-effects, and their lives. Those not on treatment were asked about their knowledge of the drugs and expectations around them; for example what information they had around planning a family.

In 2006, continuing through 2007, I also took a community focus – using focus groups to discuss health and illness. I carried out in total seventeen group discussions with either all men (7) or all women (10). Each group was formed around Brikama

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[18]Individual semi-structured interviews were arranged either through the support groups or the clinics, so as to access people who were not involved in the support groups. I aimed to interview 15 people from each group (60 from four support groups) and 15 from each clinic who were not in support groups (45). In total we carried out 87 interviews, with an even coverage across each site. The relative ease or difficulty of working through these different sites is discussed in the following section.

and the surrounding villages, with one or two groups within an *alkalo's*[19] area (or sub-*alkalo*, within Brikama town). The groups were self-selecting, formed of residents within the same or adjoining households. Each group contained between six and ten participants, with eight as the ideal number requested when we arranged the groups. These discussions were guided to ask about serious and long term illnesses in the Gambia, including but not limited to HIV, and their treatment, as well as the effects of illness and treatments on the family and community.

In depth interviews with community leaders were planned for 2007, however due to the politicisation of HIV work these were not possible. I did interview Government and NGO staff working on HIV, and continued to interact with them throughout the study period. Throughout my fieldwork I met with many people in different positions and organisations working on HIV, and so built up a picture of the HIV 'world', its players and their interactions and relationships.

I also carried out individual interviews with clinic staff from Hands on Care (6) and the MRC (8). Three interviews were carried out with RVTH staff, however, due to the difficult circumstances further interviews were not possible[20]. Eight interviews were carried out with a selection of 'traditional healers' through 2006-2007, predominantly (again due to sensitivities around the issues) towards the end of my fieldwork. These were all reached through the communities where we had carried out community interviews, using snowball sampling, and in two cases the healers were known to my research assistants.

After a planning period with the support groups, discussing whether people could come together, and the organisation and practicalities involved I started a series of workshops in October 2007. Things were not 'normal' but the initial period of shock

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[19] *Alkalo*- village chief. In the case of a larger town such as Brikama there is one overall *alkalo* and each separate district within the town also has a chief. These are customarily from the founding family of the settlement in that area.

[20] At all the clinics this was problematic as people are extremely busy, however, staff agreed to be interviewed at MRC and HoC. At RVTH the staff agreed in principle, and then became evasive. The head of the clinic first asked me to gain permission from the head of the hospital – which I already had. He then explained that they did not want to be interviewed as it was dangerous for them, especially to speak to a foreigner about HIV at this time. I respected this request and while I continued to visit and to be made welcome no staff interviews were done in this centre.

and fear had passed. There had been deaths, most saying they knew 16 people who had certainly died and there were rumours of others, and some people had now returned to the groups after being 'cured', although most had not. There was a great deal of discussion in these environments about what had happened. I planned the workshop sessions in three parts, each to discuss 'treatments', with direct reference to ARVs and clinical care within a framework of other options, but no direct reference to the president's programme. This carried through the original aims and scope of the research design, but also gave room for those who were back with the groups to discuss their experiences and decisions should they wish to.

Setting up these workshops I worked closely with the management of the groups, and arranged for group members to take care of cooking breakfast, before starting, and lunch, after the workshops for all the participants. I also paid 'transport costs' to each participant. At this point my relationship with the group members was such that I understood and agreed with their misgivings about not being properly recompensed for their time and efforts. I also did not want to give 'per diem' as this term was somehow tarnished, as will be discussed in later chapters. However, I found that people were scrupulously open and frugal with my minimal funding, sourcing ingredients and giving of their time in unexpected ways. This whole process would not have been possible, especially at this difficult time, without the cooperation, and collaboration of group members, and the previous two years of history I then had with the groups. This was made clear in discussion with women about tape recording and transcribing – "we would not agree to this except that it is you".

The workshops were arranged to run for three hours, with three different activities, facilitated by my research assistants and myself. The first part of the workshops was a discussion about support, listing and then ranking the kinds of support available in the Gambia, with a following discussion about how this could be improved or changed, and which organisations should bear responsibility. A second section asked the participants to map – as a group – the clinic environment they used (either MRC, RVTH or HoC) and discuss where they felt comfortable or uncomfortable and why, with further questions about treatment and the ease and difficulty of attending clinic as well as adherence to drugs. The third section focused on the bodily experience, using a version of body mapping (see Cornwall 1992; Macgregor 2009). However,

since this was a group activity it discussed 'a person with HIV' – depersonalising the experience and allowing freer discussion of symptoms and problems.

Interviews with health workers and NGO and government workers were all conducted in English, tape recorded and later transcribed by myself. Individual interviews and later workshops with group members were carried out in their first local language where possible, or the best-fit common language for the group. It was not possible for me to do these interviews and so I relied on three research assistants during the research period. Community focus groups and workshops with people living with HIV in the support groups were also carried out by the research assistants, although I was present for the majority of these and could interject they were led by the research assistants.

I was extremely fortunate to find three people to work with who were already skilled in community development work and participatory methods and had worked extensively on HIV and other sensitive issues as facilitators and trainers for the Stepping Stones Project[21]. This prior experience also meant that the research assistants were already known to many of the support group members, which meant that their involvement in the research did not entail any further disclosure for most participants, and that they were already accustomed to respecting the confidentiality of participants. One had also worked for the MRC as a fieldworker and so knew this environment well, and also staff at other clinics as there was a large degree of cooperation and also staff migration through the three centres.

Due to the unexpected events in the Gambia, in the president's cure and the period I spent in the UK my research activities did change. I was not able to do a second round of individual interviews with people living with HIV, as this was planned for 2007. I also did not choose to seek out prominent people – Imams and other religious leaders, or politicians – for individual interview. Again this was an activity I had planned to start in 2007, but due to the sensitivity of the issues and the potential danger to individuals in asking for their views, particularly people whose position would

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[21] See Paine et al (2002) and also http://www.steppingstonesfeedback.org/?page_id=249http://www.steppingstonesfeedback.org/?page_id=249 for description and evaluation of the Stepping Stones project in the Gambia.

identify them, I decided against continuing with this. These two activities would have benefited the research and provided a more structured chronological dimension to my discussions with individuals about their treatment, and another dimension to the 'community' aspect of the study.

Based on concerns around the sensitivity of this research throughout this thesis I have chosen to keep reference people in ways which protect their anonymity. Identifiers such as which support group, clinic or precise locality are omitted. For those within official positions, who could easily be identified (particularly in the following chapter) I have omitted any identifying reference.

2.3.2. Institutional position

This research is linked to the MRC laboratories in the Gambia. Before this research was planned representatives from NAS in the Gambia worked with staff from the MRC unit and HoC to plan the GF application, in Round Three. At that time the MRC GUM clinic was the most functional sexual health clinic in the country, and had a growing cohort of people living with HIV. Working together with the government discussions also started around the need for research, including social science research on HIV. Stigma was identified during these meetings as a priority area for research. Due to my prior interest in HIV research and my supervisor's, at that time, ongoing research in the Gambia I prepared the proposal for this research. In order to apply for joint ESRC-MRC funding this research is jointly supervised. My medical supervisor, Professor McConkey, was, at the time of application, the head of the viral disease programme at MRC Gambia, and so also directly responsible for the GUM clinic and HIV cohort.

These links were at once enabling and potentially disadvantageous. Advantages in linking with MRC were in preliminary access and logistics. My first visit to the Gambia in 2004 would not have been possible – organised and funded by the MRC. Professor McConkey's institutional and personal contacts also allowed me access to a wide range of senior people as well as to the clinics and support groups. All these meetings, each of which could have taken weeks to arrange and still not happen, were

set up within a two week visit. Before my fieldwork began Professor McConkey had left the Gambia for another position, but retains research links with MRC Gambia and remains my medical supervisor for this research.

Under guidance from the MRC/Government of the Gambia Research Ethics committee in-country supervision for this project during fieldwork was suggested. Firstly this was the head of the Translational Health Programme at MRC Gambia. However, this programme shut down during the opening stages of my time in the Gambia – during language learning. At this time I was linked to the head of research at MRC Gambia, also the head of the Viral Diseases Programme. I retained links with this person and continued to meet and discuss my progress throughout the research. The MRC also allowed me to use an office on their compound and internet access, and I could have used more of their facilities and services if I had chosen to do so.

At the opening stages of the research it was clear that a strong link between myself and the MRC could prove to be a barrier to carrying out the research, preventing people from speaking out about the MRC itself for example, and linking me with them in ways which would bias the research. The MRC are one of the largest employers in the Gambia, universally recognisable, with a fleet of white land rovers travelling between different research sites around the country. The MRC, many people told me during the research, are associated with HIV. Being visited by them or going to their compound can arouse the suspicion of family members and neighbours. As such I avoided identifying myself with them as far as possible. I reiterated on many occasions my identity as a student from the University of Sussex. However, perhaps because all research is associated with the MRC, or because of the links I did have a minority of people remained confused about my relationship with this institution.

My relationship to the MRC clinic – as a site of this research – was complicated in some ways, outlined below, by my relationship with the MRC Unit acting as my host institution as a visiting student. My relationship with my host institution became much more complex once the president announced his 'cure', particularly since I returned in January 2008 to the UK and began writing. The atmosphere of fear and paranoia which affected everyone working on HIV was all pervasive at the MRC.

There was in early 2007 a faction in the ministry of health, supporting the president, which opposed and resented the MRC. With resources outstripping local capacity in every respect, and focused on health provision as subordinate to research priorities, it was often difficult for some to accommodate such a wealthy and often self righteous guest. In this context senior staff, perhaps legitimately, feared that the Unit would be closed down and staff expelled from the country. The ways in which this institutional relationship became very difficult are discussed further below.

Clinic Access

Due to the links with the MRC my access to this clinic was very good. I attended meetings and staff trainings and was often invited to such events in advance (rather than having to find out about them myself). The staff were very open and came to consider me a colleague through my time there. While participant observation is difficult in such environments (how can you participate?) I was made welcome, and joined in with minor tasks such as sorting files and numbers. There is an issue here of confidentiality. I never used my relationship within this clinic to look at anyone's medical data, but I easily could have. This indicates the degree to which staff considered me, as with other scientific students, to be 'MRC' and so have open access to records. I discussed this issue in a training workshop on confidentiality with some of the staff and they were surprised to hear me say that I – and often these others – did not have the right to see people's records. Although my research activities sometimes put further pressure on their already heavy workload they were happy to take part in interviews, and most used it an opportunity to speak about their working experience – the positives and the negatives.

The clinic at RVTH was a young and vibrant environment. This government clinic had been set up with the GF grant, giving salary top ups as well as securing the premises and equipment. These were fortunate government workers who, on the whole, enthused about their jobs, although difficult and stressful. They had a very open and democratic way of working with each other; with weekly meetings and full reporting of cases and outcomes, as they strove to manage the difficult task of dealing with both out-patients and in-patients in different wards throughout the hospital. I was invited to attend these, and often did. I often sat in their staff room and chatted with staff as they relaxed in between sessions. They were also open in their relationship

with their patients – sharing the staff room with those who were setting up the support group and allowing them to hold meetings there also. Through 2006 this clinic and their staff were establishing themselves as competent and professional, and were proud – in 2004 nothing was in place and much had been achieved. Once the president started his 'breakthrough' programme the staff in this clinic were in a very difficult position, as is discussed in chapter six. They became the official recruitment centre for both treatment programmes. One the one hand this was unavoidable – with no option for transgression. Also there were benefits for medical personnel to endorse the president's programme – sometimes tangible in the shape of gifts or scholarships. I went to this clinic less during this period – as there was the very real threat of suddenly encountering the president and his entourage. However, I was always made welcome and staff spoke frankly about the dilemmas they faced in this dual system; specifically with reference to existing patients who wished to stop their ARVs and join the president. The precariousness of their position at this time is made clear by their refusal to be interviewed, described above.

My relationship with HoC was more problematic, and one which I struggled with throughout the research. Although I made clear my identity as an independent researcher I was often identified here as 'MRC'. In this under-resourced and cramped clinic this was not often a positive; when I wanted to interview staff and take them away from their tasks for some time, inconveniencing others. I was never allowed to join meetings or take part in staff activities, and although everyone here was happy to interact with me it was harder to observe, and almost impossible to participate. Partly this was a problem of space; there were few shared spaces where I could join the staff, so often I observed this clinic from the waiting areas. They did give very generously of their space for me to interview their patients in private, which was difficult for them to work around, and also helped me to arrange interviews and introduced patients, as in the other clinics. This separation was also related to confidentiality – and one which I respected enormously, despite the relative difficulty it caused me in observation. In contrast to the other two clinics my position as researcher at no time entitled me to be party to knowledge about patients that they did not agree to reveal, and they guarded their patients' confidentiality and decisions to disclose with an admirable strength.

2.3.3. Ethical Issues

Planning and submitting this research as a cross disciplinary study created many challenges. In applying social science methods to a medical situation this meant gaining ethical approval from both the University of Sussex and also the MRC/Government of the Gambia ethical review processes. Both of these processes were completed before my fieldwork began. A great deal of attention was given to the protection of participants in the research; their identity and confidentiality, particularly sensitive due to the nature and subject of this research.

The process of negotiation in this second process; putting a social science project through review designed for medical research, highlights some of the tensions in interdisciplinary studies such as this. Two main issues arose; that of the risks and benefits to participants, and within this issues around the informed consent process.

Although the risks and benefits faced by participants are of a very different nature when taking part in an ethnographic study and a drug trial, it is necessary to try to tally these very real concerns in research across disciplines. When speaking of 'benefits' the usual practice of compensating people for participating in medical trials, usually with free health care, is in contradiction with anthropological guidelines, and ESRC funding regulations, which prohibit payment of informants. I did not offer payment for any research participation. For the final workshops the financial support I gave for transport and the food for those participating, I judged, in this context, to be my ethical responsibility to participants. Payments, as will be discussed in the following chapters, have become an integral part of people's participation in development programmes, and specifically HIV programmes, and as such are problematic, however I felt that I resolved this issue satisfactorily in practice.

The committee, coming from the position of medical research, questioned the merits of research without direct health benefits for those taking part. This was resolved with reference to individualised gains which could come out of participation in the research. Feedback from participants indicated that many people did appreciate talking about their experiences in this way. Certainly the final workshops were beneficial for many group members, who thanked me for giving them the opportunity to discuss their situation and feelings together.

Two issues pertaining to risks to participants proved contentious; how, when and in what form informed consent is to be given; and, the issue of stigma and disclosure when recruiting participants into the research, and during ongoing interactions. Together these two issues revolve around the responsibilities of the researcher towards informants, primarily to 'do no harm'. Concerns around the control of information are particularly sensitive in research looking at HIV, with issues of disclosure and how to protect the limits participants set. I worked hard to achieve this throughout my research in a variety of different contexts, and was always careful of how to present myself and my presence depending on this.

Informed consent is a necessarily imperfect process. Full information, even where given, may be forgotten or not fully understood, and consent can perhaps never, rooted in a social interaction with its own power differentials, be meaningfully voluntary or informed. In research into HIV this is of particular importance, taking in to account the sensitive nature of the topic. My identity as a researcher often became blurred. I overheard people identify me to each other as 'MRC', or as a Peace Corps volunteer. I corrected these misconceptions where I could, but I am sure my identity was never quite clear to many. This is a difficult issue, especially as within the support groups I was automatically aware of people's status by being present. I made sure to introduce myself and my research, in meetings and within group as often as possible and asked others to do the same. Of course my identity and purpose were more important to me than to anybody else and so this need to constantly tell people who I was sometimes ignored or overlooked, and no doubt seemed tedious and irrelevant to those I sought to 'protect'.

The ethics committee stressed that each category of informant should have separate documentation, specifying their status in relation to the research, with a consent form specific to this. I felt that multiple forms could both potentially worsen the situation of the most vulnerable research participants, risking accidental disclosure, and also undermine research relationships. Since then, Dickert et al. have argued for similar exclusions, and for guidelines to reflect the difficulties when information "poses risks to the subjects the consent process is designed to protect" (2005; 33). It is interesting here that, from a regulatory perspective, the more consent, in the form of

documentation, the more 'ethical' the research, when in application the opposite would seem to be the case. In practice, even my constant verbal assertions often seemed futile in trying to convey a sense of my research to people with other more pressing concerns, certainly more forms and fingerprints would not have helped.

Within both disciplines the strictures of formal informed consent procedures are contested, on the grounds of 'trust' as a professional attribute. This conflicts with the role of ethical standards both as a 'professionalising' discourse - protecting and reinforcing the practitioner - and as a defence from abuse for participants. (see Boateng 2001; Caplan 2003; Schüklenk 2000; Silverman 2003; Strathern 2000 and Zussman 1997). In practice my consistent use of forms for interviews and taped verbal consent acted to protect me from later allegations of ethical misconduct brought by the MRC, described in the following section.

Within anthropology legitimacy is historically, with reference to previous crises within the discipline, based on the relationship or rapport with participants. Biomedicine seeks no such vindication, looking to the 'ends' of future populations to justify the 'means' of research with current ones. A separate discussion would be necessary on the ethics of knowledge use, but it is an important related issue, as the ethics of research in the social sciences spread through interactions in 'the field' to writing and disseminating information which could be potentially harmful to those it concerns. This issue in particular has been particularly relevant to my research, as is discussed below.

In this research these issues continued to be of importance throughout, as with informed consent procedures, not just on one occasion but continually renegotiated and reconfirmed. My identity itself in different spaces came to be an issue. For most of my research I lived with a family in Brikama, where I also knew many members of the support groups and patients, who lived nearby, used the same market and so on. To the family I lived with I identified myself as a researcher working on health issues. This also confused the issue in their eyes and identified me, for them, as 'MRC', despite my explanations. If I had identified myself as someone who worked on HIV I may have gained a different insight from this environment, but, I felt this would risk accidental disclosure for support group members or others who by knowing me

through my work would be identified as HIV+. I found this balance of secrecy and lies difficult and stressful. I felt that I gained less than I should have done from living within a family setting because I was on guard in some way. Reflecting upon this period I think now that – unintentionally – through this decision taken early in my research I was able to gain a very small part of understanding of the experience of people living with HIV; hiding some information about myself in some contexts and not in others. In a very real sense this also meant that for me the support groups were a very comfortable – and supportive – environment in which I did not have to think in this way.

In adopting various methods there are also ethical issues to be raised. For example, body mapping is a method that has been used to great effect in South Africa, allowing people living with HIV the space to express themselves, and providing data to researchers. In this research this method was of great value, although it was adapted to be less personal. In South Africa this is an activity carried out by trained counsellors, and in the context of other group work. In the Gambia, with very different resources available, including in terms of trained counsellors, it would seem unethical to consider running such workshops. Opening these discussions with participants could be traumatic, although potentially cathartic, processes without proper support available. The group work I did was designed to ask about the general experience of being HIV+, and of 'people' rather than oneself. Thus, although people did speak movingly about their own experiences, this was a choice that they made, as in the usual course of research, rather than due to this methodology.

2.3.4. Ethical Issues – post-fieldwork

Ethical issues became particularly important in the latter stages of my work, once I had returned from fieldwork and began to write. Due to the president's 'cure' the position of the MRC within the Gambia became quite precarious; their continued work was potentially threatened if they were seen to go against the president and his supporters within the Ministry of Health, and this was one reason for this

organisation's conspicuous silence over the 'cure'[22]. When it became clear that I could not be persuaded to keep their silence with them – a silence which I maintain is ethically spurious in itself – the MRC accused me of ethical misconduct[23]. Here I set out a synopsis of these events.

After I returned to the UK I engaged in both writing up this thesis and preparing parts of this work for publication (Cassidy and Leach 2009a; Cassidy and Leach 2009b; Cassidy and Leach 2010[24]). These papers were shared in draft form with the management of the MRC Unit in the Gambia[25]. Unfortunately sharing this work prior to publication resulted in a long and difficult set of negotiations around my ethical permissions and the conduct of this research.

The management of the MRC Gambia Unit declined to make any comments on the content of the articles, but instead stated that the publication of this material, in light of my association with the MRC could have serious implications for MRC Gambia – that they may be expelled from the Gambia. At this time we withdrew these papers from publication, in accordance with this judgement. However, it was still unclear when or if publication would be possible.

Following this exchange, a second question was raised. Rather than addressing the specific 'dangers' of publishing this material Professor Corrah approached Professor McConkey to question whether the ethical permissions obtained in advance of beginning my fieldwork were no longer valid. This claim was based upon a 'changed' focus of my research, on the grounds that the president's intervention in HIV treatment sufficiently changed the circumstances and required a second application to the Gambian SCC/Ethics Committee. This claim was countered by email, by

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[22] Senior management at MRC Gambia gave strict instructions to all staff not to comment on the president's 'cure'. The unit never gave any official reaction or statement. Papers shared with the unit in 2007 prior to publication were deemed to be a risk – and so were withdrawn from publication until a later date (Cassidy and Leach 2009a, 2009b)

[23] A theme which is raised through this thesis is that of silence – and its operation as a positive social value in this context, although one which acts to protect the powerful. An interesting comparison is the MRC Gambia's use of silence here.

[24] The published versions of Cassidy and Leach 2009b and Cassidy and Leach 2010 were substantially changed to refer only to events prior to January 2007, and so not include material on the presidential 'cure'.

[25] These papers were first put forward in November 2007, prior to the end of my fieldwork, then again once I returned to the UK in May 2008.

Professor Leach, with reference to the relevant ethical applications and permission documents. At this time we received no further response and believed that the matter had been resolved. Although, again, with no clear plan for future publication.

However, the management of the MRC (Head Office, London) then made a formal complaint to Professor Leach. This complaint raised two issues: firstly, that the research did not have the appropriate ethical approval and permissions, and secondly, that the language used could pose a threat to the safety of the MRC staff in the Gambia, were it to be in the public domain.

In November 2008 a meeting was held at MRC head office in London which Professor Leach, my supervisor, and Professor Haddad, the Director of IDS attended, to consider these allegations with MRC staff and ethical advisor[26]. Although this meeting discussed the issues, and sought to clarify both the specific allegations and responses the deadlock remained.

Through December 2008-January 2009 correspondence continued, clarifying some issues and discussing others. The MRC made a formal complaint to the University of Sussex on January 15th 2009, instigating an internal process of investigation. In relation to this process I met with Professor Richard Black (March 20th 2009), the Director of Doctoral Studies and outlined for him my position on these allegations. I outlined both my actions in conducting my research and my understanding that these allegations were not related to a concern with the ethical, but more a deliberate attempt to prevent publication using the bureaucracy and process of ethics. While he understood my position he recommended that the allegation be upheld (he had an option to dismiss at this time), in order that lessons could be learnt. University procedures then required a formal investigation of these claims, by a panel appointed by the University. This panel of three people included both internal and external investigators from across different disciplines (medical ethics and social science). The panel was arranged for April 27th 2009.

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[26] Professor Tom Meade, Professor of Epidemiology (Emeritus) LSHTM, member of the MRC ethics, Regulation and Public Involvement Committee,

In the meantime a further meeting was arranged with both MRC and ESRC staff to discuss the potential risks and dangers in publishing this research (March 16th 2009). This was a useful meeting which addressed the risks to all concerned: the participants in the research, staff of the MRC as well as other clinics and agencies who had been involved in this research, risks to the institutions, including the MRC and also to myself. This meeting also allowed us (my supervisor and I) to request specific comments on the text from those present and from the Gambian MRC Unit management. From here it was agreed that, subject to resolution of the ethical complaint, publication of my research findings would be possible. It was agreed that these publications would also be sent to MRC communications office, as well as future publications, so that they could assess the potential risks in publication for their staff.

The formal investigation of research misconduct considered all the documentation of the case: a dossier prepared by Professor Leach including all relevant ethical applications and permissions as well as a chronology of events including emails and communications from 2007-2009. Professor McConkey also sent a statement detailing his involvement in my research and his thoughts on the accusations. The MRC complaint was also included, with an article which detailed a recent case of a missionary couple who had been arrested in the Gambia for sedition[27]. After considering the evidence presented the panel dismissed any claim of ethical misconduct.

This outline gives an indication of the events – although not the time and stress – involved in this process. From the time that ethical questions were raised until they were dismissed it was unclear whether I could use or publish my research findings. This process, the motivations of the different institutions and actors, opens many questions around the role of funding bodies in research and research governance (this research was jointly funded by an ESRC/MRC studentship), as well as the ethical obligations of international research organisations, such as the MRC, in the host countries where they carry out research.

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[27] British missionaries David and Fiona Fulton jailed in the Gambia, The Times online December 31st 2008 http://www.timesonline.co.uk/tol/news/world/africa/article5421148.ece

3. Global Spaces

While this research focuses on the ways in which HIV treatment plays out in one setting – a particular and local set of circumstances – it can also be argued that many of the assumptions, programmes and practices which make up everyday life for people living with HIV in the Gambia have travelled from elsewhere.

Discussion of HIV, and its treatment, necessitates a discussion of the ways in which at a global level ideas about good practice are taken up and reinterpreted through various national programmes, and so experienced in many different areas of the world. Nguyen (2005) and Rose and Novas (2005) describe a biological or therapeutic citizenship, a travelling set of ideas attached to biomedical conditions, and the ways in which they are framed. As discussed in Chapter 2 the ways in which HIV and AIDS have been envisioned since the 1980s are linked into wider fears, beliefs and sets of power-knowledge relations, which shift and are challenged over time.

This chapter outlines the ways in which the global appears in the lives of people living with HIV in the Gambia – aspects of the "global assemblage" (Ong and Collier 2005) that is 'Global AIDS' or the 'AIDS Industry' (Pisani 2008). Here I first set out how 'Global AIDS' is configured, through a global architecture of funding and policy networks. The second section looks specifically at the Global Fund, as the major funder in the Gambia. The third section looks at how Global AIDS and the Global Fund's funding play out on the ground in the Gambia, through the networks of institutions and individuals living with or working around HIV, and how the global becomes local in this case. Following this I discuss the ways in which the presidential treatment programme is also 'global' – and how in this sense it can be interpreted as a backlash against these channels of funding which supersede the power of the state.

3.1. Global AIDS Funding

Global Health is a relatively new term, referring to a new set of structures which has emerged in response to global problems. These structures come with a particular set of assumptions and meanings, coming out of international efforts to tackle problems such as HIV around the world. This new terminology and the new structures that are integral to it – the architecture of global funding for health – move away from

internationalism and relationships between states, to globalism and supra-state authority structures.

> A steady evolution of philosophy, attitude, and practice has led to the increased use of the term global health. Thus, on the basis of this analysis, we offer the following definition: global health is an area for study, research, and practice that places a priority on improving health and achieving equity in health for all people worldwide. Global health emphasises transnational health issues, determinants and solutions; involves many disciplines within and beyond health sciences and promotes inter-disciplinary collaboration; and is a synthesis of population-based prevention and individual level clinical care.
>
> Koplan et al 2009; 1995

The size, scope and resources of these health programmes coupled with a moral authority to act upon global threats gives them a unique power to act around the world (deWaal 2006; Dry 2008). However, it is not only the fact of transnational health issues, and a synchronised effort to alleviate them which inspires such a shift. Although the new Global Health Initiatives (GHIs) act towards "achieving equity" (Koplan et al 2009) there is a tension in this reordering of regimes where a "diversity of multilateral systems – multinational companies, religious organisations, UN agencies, and other NGOs – intervene to deal with specific, situated and practical problems of abused, naked and flawed bodies… In short, the counterpolitics of survival are crystallised through the interrelationships of biopolitics, labor markets and systems of virtue" (Ong 2006; 24).

GHIs form a new generation of global philanthropy in the health and broader science, technology and development fields, and a new generation of global public-private partnerships; "Since 2004, the Global Fund, PEPFAR, and the World Bank's MAP (i.e. 'the big three') have been providing large volumes of new money for HIV/AIDS programs. By 2005, they were transferring (i.e. disbursing) more than $3 billion per year, with over 70% of this total coming from PEPFAR" (Bernstein and Sessions 2007). The volume of funding for health has risen sharply in the last 20 years, with the proportion channelled by GHIs making up the largest part of this, and funding for HIV also dominating. This is further complicated by a rise in 'philanthro-capitalism', with what some commentators see as the overtaking of health agendas by organisations such as the Gates Foundation (McCoy et al 2009), and the blurring of

boundaries between commerce and compassion by the (RED) campaign (Richey and Ponte 2008; Richey 2009).

> DAH [Development Aid for Health] grew from $5·6 billion in 1990 to $21·8 billion in 2007. The proportion of DAH channelled via UN agencies and development banks decreased from 1990 to 2007, whereas the Global Fund to Fight AIDS, Tuberculosis and Malaria, the Global Alliance for Vaccines and Immunization (GAVI), and non-governmental organisations became the conduit for an increasing share of DAH. DAH has risen sharply since 2002 because of increases in public funding, especially from the USA, and on the private side, from increased philanthropic donations and in-kind contributions from corporate donors. Of the $14·5 billion DAH in 2007 for which project-level information was available, $5·1 billion was for HIV/AIDS, compared with $0·7 billion for tuberculosis, $0·8 billion for malaria, and $0·9 billion for health-sector support.
>
> Ravishankar et al 2009; 2113

Between these funds there is competition for resources, channelled from governments and private donations, and repetitive problems in securing pledges or donations and replenishing the coffers for these large funders (Bezanson 2005; Brugha et al 2005; UNAIDS 2009; Chambré 2006)[28]. The GHIs' main purpose is to "attract, manage and disburse" (GFATM 2002; 1) funds, but the power of such vast funding streams necessarily shapes the priorities of recipients, and the programmes they fund. The PEPFAR positions on family planning and Commercial Sex Workers are the highest profile example of funding steering national and local programmes and projects through agenda setting (Sepulveda et al 2007; OSISA 2007; Crane and Dusenbury 2004). However, the legitimacy of GHIs dominance in setting and steering the global health agenda has been called into question recently; as a Lancet editorial asked "Who runs global health?" (Lancet 2009; see also McCoy et all 2009; Biesma et al 2009; WHO Maximizing Positive Synergies Collaborative Group 2009; Sridhar and Batniji 2008; Prah Ruger 2007).

GHIs, despite such scrutiny and criticism, now make up the dominant architecture of global funding, and thus, alongside older policy leaders in the UN system, also global

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[28] See also 'Global Fund says faces about $3 bln aid shortfall'
http://www.reuters.com/article/middleeastCrisis/idUSL3579451

thinking on issues such as HIV; framing the problem and therefore potential solutions. Brugha et al (2005) outlines how country proposals reflect what the Country Coordinating Mechanisms[29] feel will get funded, rather than being led by national priorities or the realities and particularities of the epidemic. However, such discourses and power-knowledge relationships can be negotiated to some extent, and different positionalities shape the degree to which people, and organisations, at different points along these funding chains are able to do this.

Within each country which gains access to these international streams of funding are a plethora of intermediary organizations. These range from international NGOs with well established HIV programmes and policies, to local implementing partners, including the support groups and local organisations run by recipient groups, in this case people living with HIV. As sub-recipients (SRs) of the GF grant these organisations are also tied into expectations around action, and reporting, which can be difficult to maintain. For many recipient groups this, in reality, means that they are on the end of a chain of funding organisations with little control or say over the design or implementation of projects (Cassidy and Leach 2009b; Robins 2010).

These relations and the dominance of certain discourses in HIV can be seen to play out in practice in many ways. In Burkina Faso, Nguyen (2005) describes "the onslaught of empowerment workshops, role-plays, self-esteem exercises, and the panoply of confessional technologies that trained people with HIV to "live positively" and "come out in the open", in order to "break the silence" and "overcome the stigma" of living with HIV in Africa. Nguyen writes from 2001, but the same strategies – the same words – existed in similar settings in the Gambia in 2006-8. The advent of ARV treatment brings with it not only hope and health but also self-

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[29] "Country Coordinating Mechanisms are central to the Global Fund's commitment to local ownership and participatory decision-making. These country-level multi-stakeholder partnerships develop and submit grant proposals to the Global Fund based on priority needs at the national level. After grant approval, they oversee progress during implementation.
Country Coordinating Mechanisms include representatives from both the public and private sectors, including governments, multilateral or bilateral agencies, non-governmental organizations, academic institutions, private businesses and people living with the diseases.
For each grant, the Country Coordinating Mechanism nominates one or more public or private organizations to serve as Principal Recipients."
From the Global Fund website; http://www.theglobalfund.org/en/ccm/

reinforcing sets of scripts and practices: around the drugs themselves, proscriptions around their use and misuse, as well as the necessity for VCT (although counselling was unknown in such contexts previously[30]), of biomedical tests and numbers, and disciplines of the self, surrounded in phrases such as "rights and responsibilities" (see Danziger 1996). Schepher-Hughes (1994) commented on the development of an "uncanny consensus" among those working in HIV. These travelling discourses are powerful but they are also shifting and contested, and sometimes contradictory. The enforcement of disclosure in order to access treatment, for example, brings into sharp relief the contested ground between public health perspectives and a stress on individual human rights.

The following chapters each bring out some of the ways, in practices, language or assumptions, that these 'global assemblages' (Nguyen 2005) appear in the different spaces which people living with HIV move through. The following sections of this chapter describe the particular structures and dynamics of the GF in African settings and in the Gambia in particular; its machinery and the ways in which this is shaped by this context and also shapes it. Here also, I begin to tease out the understandings of people living with HIV in this context within the structures and systems which shape their experiences; the web of connections from the global to the national and local, and the invisible context of this research.

3.2. *The Global Fund in a world of international health funding*

In many countries the resources allocated for HIV by global funders dwarf the resources available through public coffers. In Uganda and Ethiopia, once AIDS money began flowing from all three funders in 2004, the amount of money provided quickly approached, and by 2005 had exceeded, the governments' 2003 budgets for the entire health sector (Bernstein and Sessions 2007). The scale of these resources, and their dispersal through vertical, disease-focused programmes, has given rise to heated debate about the extent to which the globally-structured 'AIDS industry' may be undermining national and local health systems and their broader priorities.

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[30] Counselling services introduced in the Gambia are attached to disease or MRC research programmes (see also Bledsoe 2002 for discussion of family planning) however counselling is largely a process of information transfer rather than emotional support, and bears little resemblance to VCT counselling as would be found in contexts where counselling is a more accepted and established practice with formal training and certification.

The GF was set up in 2001, in order to manage the enormous funds being mobilised in response to what were increasingly seen as global health threats, including the demands of scaling up ARV treatment. The GF's first principle is that "The Fund is a financial instrument, not an implementing entity" (GFATM 2002; 1). As such it channels funding into in-country structures. However, such structures often do not exist prior to engagement with the GF and so are created in order to access this funding stream.

In particular the GF explicitly presents itself not as a top-down global mechanism, but as 'uniquely' locally responsive. The Fund defines itself as offering an innovative approach to international health financing based on partnership between governments, civil society, the private sector and affected communities.

> The CCM model used by the Global Fund encourages new and innovative alliances among partners in recipient countries, drawing on the active participation of civil society as well as government, multilateral and bilateral partners and NGOs. This model has provided an opportunity for greater participation and collaboration between all sectors involved in the fight against the three diseases.
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> GFATM 2007; 10

In line with the 'Three Ones' international campaign for more strategically focused and collaborative work in HIV programmes[31], the GF prefers to work with one Co-ordinated Country Proposal (CCP) through a Country Co-ordinating Mechanism (CCM) which becomes the focus for programme accountability. This national level planning at once implies country 'ownership', and also, within these structures, civil society representation and 'ownership' is a condition for programme funding.

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[31] The 'three ones' guiding international collaborative effort and funding in HIV work were agreed at a UNAIDS coordinated forum at ICASA in 2003, and further discussed by a UNAIDS and DfID coordinated meeting in 2004

- One agreed HIV/AIDS Action Framework that provides the basis for coordinating the work of all partners.
- One National AIDS Coordinating Authority, with a broad-based multisectoral mandate.
- One agreed country-level Monitoring and Evaluation System.

(see also; http://www.aidsalliance.org/sw20857.asp;
http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/EXTAFRHEANUTPO
P/EXTAFRREGTOPHIVAIDS/0,,contentMDK:20699584~pagePK:34004173~piPK:34003707~theSit
ePK:717148,00.html)

However, this leads to the establishment of structures to ensure this – and access this funding – where none might have existed before. These structures, rather than being unique and inclusive, perhaps reflect a broader move towards the mantra of partnership among development donors.

The other key structure in the GF's funding framework is the Principal Recipient of a country grant. This is the organisation to which funds are channelled, and which carries out disbursement to sub-recipients as identified in the CCP. Principal Recipients are typically a government ministry such as the Ministry of Health, or a government agency such as a National AIDS Council. In some cases, a Principal Recipient may be a non-governmental organization or a UN agency. When sub-grants are made, the Principal Recipient remains responsible for reporting to the Global Fund on the use of funding.

In principle the GF works in new ways to ensure representation from affected communities and their organisations, and to directly address their needs. In practice the extent to which this is possible is variable, and dependant on the various structures and power relations this involves: state authority structures, NGO and other intermediaries. The GF framework document does allow the possibility - in political contexts where governments are illegitimate, in conflict or suppress civil society activity - of forging funding partnerships directly with civil society. The creation of the civil society Observatoire (watchdog) in reclaiming the GF negotiations in Senegal, and the ANCS acting as the first NGO PR, are one positive example (Alliance 2007).

These structures do, in theory allow for such shifts, and for civil society organisations to leverage for their priorities within the GF. Government representatives have sometimes critiqued the CCM model for this very reason (Brugha et al 2005).However the reality is that the national framework and structures mediate in such a way as to prevent this in many cases. In the Gambia there was some discussion of the PR role being put out to tender, and the role was advertised in the main national newspaper; however, it has remained with the NAS within the government.

In other country settings, too, comparative tracking studies have begun to indicate a range of problems in attempting to operate effective CCM partnerships. Thus in Uganda, Tanzania, Zambia and Mozambique (Brugha et al 2005), CCM forums revealed major tensions between government bodies and between government and civil society over the distribution and use of new funds for HIV control programmes. These tensions were not caused by (and had preceded) the Fund, but were exposed and heightened by the Global Fund process. All four countries encountered, to varying degrees, similar problems around the ineffective representation and participation of civil society constituencies, and a dominance of high-level line ministry representation, reflecting the high political stakes of the GF process.[32]

Civil society critique - for instance in Mozambique and Uganda - has also turned on the dominance of government bodies as principal recipients, linked to tendencies for them to be the main beneficiaries of GF resources (Brugha et al 2005). In Uganda, for example, civil society organisations were by 2004 highly vocal in their critique both of government and of the GF in this respect. In Zambia, the appointments of an NGO and a faith-based body as PRs were seen as addressing a fundamental concern to see a significant proportion of Global Fund resources channelled through non-government bodies, in keeping with the claimed spirit of the Global Fund approach.

As Brugha et al (2005) describe, such struggles and tensions around the meaning of partnership in GF processes revealed deeper tensions: around the relative importance of plurality amongst multiple stakeholders, versus co-ordinated stewardship by government, and more fundamentally, ideological questions around the legitimacy and role of government in a world of globalised networks and partnerships involving civil society organisations.

Meanwhile, guidance and guidelines to CCMs from the Global Fund for dealing with such tensions has often come late, if at all, and has paid little heed to the contextual power dynamics that caused them. Nor have processes been established for brokering

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[32] This is despite the fact that in practice line ministry representation at CCM meetings was often too low to ensure effective momentum in mainstreaming and inter-sectoral commitment around HIV activities (Brugha et al 2005)

agreement amongst the different stakeholders on their respective roles and responsibilities.

Most GF tracking studies have stopped at the level of the Principal Recipient, and do not characterise or disaggregate within 'civil society' as recipients of GF resources. Others have, however, pointed to the low proportion of HIV funding from all sources that reaches community groups (Foster 2007) - in the case of the GF despite a stated commitment to reaching affected communities. A recent study of Lesotho, Malawi and Swaziland found that only 10% of Civil Society Organisations (including NGOs and community-based organisations) received about 73% of the funding to civil society (Birdsall and Kelly 2007). A very small proportion of community-based and grassroots groups, such as groups of people living with HIV, are thus receiving funding. More significantly, two-thirds of all CSO recipients of support receive it through intermediary NGOs or umbrella structures and programmes, rather than directly from vertical funders such as the GF. This suggests the key role of intermediary organisations in shaping access to resources. Indeed the fastest growth in scaling up funding to civil society has occurred amongst intermediaries, and their role has been key in mobilising other civil society organisations, including grassroots and community groups - to take up HIV work (Birdsall and Kelly 2007).

Birdsall and Kelly (2007: 12) draw attention to how 'Centralised vertical programmes and channels… are criss-crossed at all levels by a flurry of smaller-scale activity that may or may not be linked to the official response framework.' Insightfully, they suggest that from very heterogenous roots, those activities that do become linked tend to group around a relatively standard, ordered set of interventions. These are situated along the continuum from prevention through to care and support, treatment and rights, and are clustered under broad headings: prevention (VCT, behaviour change communication, prevention of mother-to-child transmission (PMTCT), activities targeted at high risk and vulnerable groups, control of sexually transmitted infections (STIs, blood safety, infection control, workplace interventions), care and support (home-based care, support groups, networks and associations of people living with HIV, treatment of opportunistic infections, nutrition, psychosocial support), treatment (ART), impact mitigation (support for orphans and vulnerable children, income-generation projects, food security) and rights (anti-stigma and discrimination,

leadership, human rights, and the 'greater involvement of people with AIDS' (GIPA) principles). Many national plans - and proposals to international bodies such as the GF - contain these standard elements, despite widely varying epidemiological and socio-political contexts. As they put it,

> The comprehensive response framework seems to leave little space for anything short of addressing all elements simultaneously. This is strengthened by the fact that core elements of these responses are increasingly linked into global targets – the '3 by 5 campaign' and the campaign for universal access to prevention and treatment – which are structured around the same intervention categories
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> Birdsall and Kelly 2007: 16

Put another way, the global AIDS funding industry is helping to put into play a standard set of solutions, responding to a standardised set of framings of the problem that link biomedical notions to what have become globalised received wisdoms about HIV and AIDS. These globalised framings do, of course, contain minor variations and contestations, responding to the diverse positions, histories and ideologies of different agencies. The framings of these main funders, and the structures that they create on the ground, also vary, but it is beyond my focus here to compare them. However, these are largely variations within a broad, dominant contemporary framing of AIDS as an exceptional epidemic requiring exceptional responses which, currently, emphasise biomedical solutions and individual rights and responsibilities (Edstrom 2008; Robins 2005).

Brugha et al (2005) point out a competitive dynamic within countries' engagements with the GF process that can be seen to perpetuate such globalised constructions. Thus in many cases CCMs have become focused on trying to identify what the Global Fund was likely to fund, rather than what internal discussion suggested their countries might need. In the case of Uganda, for instance, when early proposals focusing on country priorities for system-wide strengthening were rejected, the CCM reverted to disease-specific proposals based on the belief that these were more likely to be funded. A focus on proposals that directly tackled disease - such as ART - also reflected perceptions that the GF would be more likely to respond to these because they could be expected to lead to impact indicators of the kind that donors liked. This in turn responds to the mantra regularly repeated by the GF's Executive Director: that

the GF's mission is to 'raise it, spend it, prove it,'[33] emphasizing the drive to raise large sums of money, to disburse it quickly, and then to demonstrate concrete results at the country-level.

Structures of funding access, globally and in-country, can thus be seen to interplay with an epistemological standardisation of problem-and solution interpretation around HIV. The influence of such global framing, it can be argued, often comes to extend beyond those organisations actually receiving funding through globalised vertical programmes and the intermediary organisations that shape access to them. A wider global epistemic community (Haas 1992) or culture (Knorr-Cetina 1994) is emerging around HIV through the array of global networks and forms of knowledge exchange that these programmes are part of. As Nguyen (2005) shows, this has come to include citizens' networks and enwraps forms of therapeutic citizenship constructed around particular, globalised ideas of what it means to be HIV-positive. While specific struggles may be taking place over who receives or fails to receive funding, and over precise programme priorities, much of this debate and struggle is now taking place only as minor bit-parts within the broader epistemological play that is AIDS globalism.

As I now go on to explore in the next section, in the Gambian situation, such tensions - and their playing out only within a broad epistemological context in which HIV and AIDS are seen as biomedically-defined problems amenable to certain sorts of response - are evident.

3.3.   *Global AIDS funding in The Gambia*

The first case of HIV in the Gambia was identified in May 1986; the Director of the British-funded Medical Research Council laboratories (MRC), then working as a physician, remembers carrying the samples back to the UK to run the tests. In 1987 the then Ministry of Health, Labour and Social Welfare established the National AIDS Control Programme (NACP), and parliament also approved the foundation of

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[33] "The Global Fund's work is guided by three major imperatives: Raise it, Spend it, Prove it" available online;
http://www.theglobalfund.org/documents/publications/brochures/whoweare/TGFBrochure_GlobalFund sWork.pdf

an advisory committee, the National AIDS Committee (NAC). The response at this time was strongly led by medical and public-health perspectives and predominantly focused on Information, Education and Communication (IEC) activities. Funding came from WHO's Global AIDS Programme. In 1990 the first five year Development Plan, again mainly WHO and UNDP sponsored, was established. However aid streams were cancelled at the time of the coup on July 22nd 1994, when the APRC and the current president took power.

In 1995 a first attempt was made to embark on a more integrated, multi-sectoral response to HIV - again funded by UNDP and WHO when the NAC was reconstituted. As in many other countries at this time, it was realised that "a more targeted and intensified response is required to create awareness, provide treatment, care and support as well as mitigate the impact of the disease on individuals, families, communities and the nation as a whole".[34] Many elements of what were becoming standardised global packages began to be put in place, although interventions taking a bottom-up community perspective - such as the participatory learning and action interventions of Stepping Stones - were also evident at this time.

The year 2000 was a landmark for HIV programming in the Gambia. An application was submitted, and approved in September, for MAP funding from the World Bank. The Gambia was among the first countries to access HIV/AIDS Rapid Response Project Funding (HARRP). The programme – providing US$15 million – came into effect on 31st July 2001. The first National AIDS Forum was also organised in 2000, held at the Kairaba Hotel on November 1st. Notably the president attended this event, and gave the fight against HIV his, and his government's, full support, stating that no civil servant would be sacked based on their HIV status:

> The HARRP supported the creation of the National AIDS Council which is chaired by the President His Excellency Dr. Yahya A.J.J. Jammeh. The National AIDS Secretariat (NAS) was also created to coordinate the response and serve as the technical arm of the NAC. At the decentralised levels the NAS created Divisional/Municipal AIDS Committees (DAC/MAC). The

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[34] Quotes in this section come from interviews and prepared statements from Gambians with long experience of working on HIV in the Gambia, working within various organisations as well as government

membership of both the NAC and DAC/MAC was multi-sectoral with the view to enshrining the key strategies of cross-sectoral approach to the national response to HIV/AIDS.

Some describe the HARRP money as 'seed money' for the main Global Fund grant; although unlike Global Fund grants it requires repayment with interest. In The Gambia, it was HARRP funding that allowed an HIV treatment programme to get started, and to get some patients onto ARVs - those who were waiting at the main two operational treatment centres. The advent of ART in the Gambia, as in other contexts, radically altered the relationship between patients and treatment centres, as one health worker reflected:

> The treatment programme? This clinic is exceptional, in the country. I think so. Generally, looking at those who are on, who started ARVs up to now, I am contented. I remember some people who even gave up coming to this clinic, because they thought, I mean, they will not have any benefit, coming to this clinic, is only coming, bleeding, you know? Some of them don't understand. They are coming here, only sucking up their blood, getting only small drugs. It's not beneficial. I know of people who advocated going to Senegal to get drugs. They are now with us. They are happy.

The HARRP programme had four main streams: institutional capacity; multi-sectoral responses; health sector response – including some ARV treatment as well as VCT, PPTCT, STI treatment, training and strengthening HIV-TB links; and community and civil society initiatives.

Source: The Gambia HIV/AIDS Rapid Response Project Borrower's Implementation Completion and Results Report, December 2006

Although there were problems with implementation, it is arguable that these funds enabled the setting of a broad agenda for HIV work in the country. They also enabled support groups for people living with HIV to come together for the first time:

> NAS, through HARRP, lead with resources, and set the agenda for collaboration with civil society, from CBOs to NGOs to the UN…NAS through HARRP created an environment, especially in political involvement. Senior government staff were able to talk on HIV issues, the president called for VCT, and an end to stigma.

HARRP put HIV at the forefront of the development movement, it was a wake up call at all levels…resources were made available to organisations that would've never had access before, and would never have worked on HIV. Santa Yalla [support society] came up, as they had resources, and also others had resources to do things with Santa Yalla.

HARRP funding allowed for the setting up of NAS, and the writing of the first strategic plan for the Gambia, and so enabled the country to access Global Fund financing. The Global Fund grant, of US$14million, successfully applied for in Round Three, came into effect in 2004, and took over ARV treatment provision as planned. HARRP prevention programmes ran until the end of the life of the loan, 21st December 2006.[35]It was planned that these prevention activities would also be taken over by further future successful applications to the Global Fund, as prevention programmes were not a major component of the original Round Three grant. This has not happened. Applications to both Rounds Five and Six have failed, with some strong criticism from the Global Fund of the way in which the applications were structured, and so with much internal criticism in the Gambia for those involved. However, under the original GF grant, HIV programmes in the Gambia have continued to grow, with six ARV treatment centres[36] now operating around the country, as well as 24 VCT centres, and 17 PPTCT sites.

International constructions of HIV and AIDS – as discussed in the previous chapter – shape how thinking changes, and tallies with the political economic and social aims of both the national structures and international actors working in different contexts. The programmes which have emerged in the Gambia, including ARV treatment and a range of programmes from prevention to care and support, exemplify the assemblage of 'Global AIDS' translated into this setting. Elements of what 'should' be done are transplanted from elsewhere; ideals of networking between the support groups or the

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[35] HARRP had been due to finish in July 2005, but was extended until the December of the following year.

[36] Upcountry Treatment Centres in Bwiam, Farafenni, Bansang and Basse have been beset with problems. Farafenni had one patient start treatment who later died. Basse is run by a Faith-based NGO, and is generally the best centre. However, they have never had a doctor to prescribe drugs and present cases to the national eligibility committee (in Banjul), patients and staff were visiting the doctor in Bansang, however there is now no physician here either. These treatment centres continue to be operational with the continued support of NGOs (in Basse and here in Kombo/Western Division) and the dedication of both their staff and, especially, patients to travel the length of the country to centres in Brikama, Banjul or Fajara to collect drugs for themselves and others.

'right' way to organise. However, all such programmes are mediated and negotiated by people on the ground who express their needs through available channels, and successfully navigate procedures and protocols to do so (Cassidy and Leach 2009b).

Support groups for people living with HIV are positioned within 'civil society', as the most legitimate to act according to community needs. Although this is problematic its power is demonstrated in, for example, the Global Fund's grant giving structures and their insistence on civil society inclusion. Seckinelgin (2006) describes a 'looping' in the donor creation of civil society in relation to international HIV work, which can then respond to donor demands;

> International actors consider actors who are able to participate in their frameworks as representatives of civil society, independent of any concrete evidence to the link between civil society and the way people live through other social forums. In addition it ignores that they define this civil society to which the people are responding.
>
> 2006; 21

So a system exists in which people 'play the game' and learn to enact the procedures and language in order to access funds. People also strive to 'work the system' at many levels. For those within the support groups there is much suspicion as to where the money 'for them' goes once it arrives in the country (Cassidy and Leach 2009b; Cassidy 2010). Many people feel that those in intermediary positions – in government and other NGOs – 'eat the money' which was meant for them, while they struggle to survive. On different occasions group members would discuss individuals they saw to be gaining, the improvements they had made to their homes, vehicles and so on. Within the support groups, particularly in the early stages in 2006, many people felt that those in control of the funds did not understand their priorities and it would be better to give them the money to split between them and decide individually what to do – attending to daily costs and family pressures. This, of course, is not in line with the way international funding is accounted for, but a tension grew up on both sides; around a lack of professionalism and transparency perceived by those channelling the funds in the groups, and a lack of transparency and trust – 'NAS treats us like children' – perceived by group members. Despite the high degree of invasive intervention of HIV programming in people's lives – their relationships and bodily functions – there was little perceived control over the patterns of such programming

for those concerned. An acute awareness of the assemblage, and the funding and players within the Gambia, still made few avenues available to join, affect or effect its workings.

Thus, by 2006 a powerful global assemblage had become rooted in Gambian settings; linking particular kinds of (biomedical) framing of HIV problems with particular solutions available through particular institutional and funding structures. The following chapters pick up on these themes, particularly 'treatment spaces' and 'support society perspectives' where the 'global' becomes visible in everyday life. These chapters explore the sense that people living with HIV made of these and how they engaged. It was into this field of power-knowledge shaped by AIDS globalism that the presidential treatment programme emerged.

3.4. *The Presidential 'AIDS cure'*

The president's 'breakthrough' is arguably just as 'global' as biomedically rooted treatment and the programmes which surround it. His herbal massage and drinks were based upon a secret recipe of 'seven herbs named in the Koran', as is discussed in greater detail in the next chapter. It appeals to understandings of disease and therapy that are rooted in herbal and Islamic notions - in contrast with biomedicine. The president's framings of HIV and its treatment were strongly linked to political claims and authority structures different from, and indeed constructed in opposition to, those of the global scientific and funding community. Thus in his speech on 31st July 2007 discharging the first and second batches of patients, Jammeh linked his interest in curing HIV to strong pan-Africanist and anti-western discourse[37]. Implying racist reasons for HIV being primarily a 'scourge' on Africans, he constructed 'global' science and funding for HIV and AIDS as part of a continued western project of colonial and post-colonial domination. From the beginning the press in the Gambia set out a strong position on the 'racism' of implying that the answers to health problems can only come from the west, and linking this 'imperialism' with financial gains to be made by pharmaceutical companies in maintaining their monopoly. Large

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[37]"President Jammeh's speech, which strongly featured his pan African ideology, lashed out at the colonialists for the exploitation of the mineral and natural resources of Africa. He said the West would disagree about his ability to cure the AIDS Virus because of the billions of dollars they get from the HIV/AIDS Campaign Fund." From the Daily Observer 31st July 2007, reproduced on the president's website; http://www.statehouse.gm/hivaidspatients-discharge_310707.htm accessed February 3, 2010.

scale funding for HIV was portrayed as a way for western governments and pharmaceutical companies to line their pockets through the sale of expensive drugs. And he and his supporters construct scepticism about his cure claims in these terms:

> President Jammeh's discovery of the medicine to cure HIV/Aids attracted unjustifiable criticisms by many sceptics, in particular, so-called western medical practitioners who have a vested interest in ensuring that no one should claim to have a cure for HIV/Aids so long as these discoveries are not from the western laboratories
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>   D. A.B.S. Taal, ' Jammeh's Aids cure, a victory for humanity', Jun 22, 2007[38]

In this vein, the president's treatment regime appears as a backlash or counter-politics to the global (western) hegemony represented by institutions such as the Global Fund, taking on the characteristics of a new global conflict:

> President Jammeh is right when he says that we live in a difficult world as the global powers that would want to thwart or derail the efforts of the President, thus, putting the lives of many Africans in Jeopardy. Indeed, the discovery of the cure for HIV/Aids by President Jammeh has led to a new global battle against their discovery and for that matter against President Jammeh and the people of The Gambia. Indeed, a global fight has been unleashed on us but it is now certain that President Jammeh and the people of The Gambia will triumph
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> Ibid.

Thus Jammeh's stance could be seen as a form of resistance to the power of discourses based in 'western' biomedicine and ideals, and with vast funding, which bypasses the machinery and control of the state.

The president's treatment regime appeals to a variety of quite different notions from the global therapeutic citizenship represented by the GF. In claims about a 'Gambian cure', a kind of therapeutic nationalism is invoked. Sometimes this becomes an appeal to pan-Africanism. Within The Gambia, invoking the power of both 'traditional' and Islamic healing was a means to appeal to political constituencies and related notions constructed in relation to these powerful authority structures. Alongside these,

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[38] http://www.statehouse.gm/hiv-editorial.htm

however, the president's claims also constructed the possibility for an alternative, and equally global construction of his 'cure'. In several statements, he and his supporters referred to The Gambia's 'new allies' in Iran and the Middle East[39], invoking pan-Islamic notion of allegiance that is no less global than that suggested by the GF, but constructed along very different axes of local-global power in a fraught contemporary world and one of high Gambian outmigration and diasporic connection.

Factional Politics – Global Fund structures in practice

This international positioning, with suggestions of alternate power bases does not detract from the fact of GF funding in the Gambia, for HIV, TB and Malaria programmes[40]. The scale of these resources, as elsewhere, dwarfs national capacity, and has its own methods of reporting and accounting which fall, to some extent, outside the control of government. These resources, and the institutional arrangements for their control became complicated at the end of 2006.

Prior to the president's announcement of a 'cure', the position of NAS without HARRP was already precarious: still not officially endorsed and constituted by the government; having failed to procure more funds, and having had its head removed - a scapegoat, many said, for the failures of the unit in general. Then, suddenly, the NAS was moved, shifted from the office of the president to be a subordinate to NACP and the Ministry of Health (MoH). Many people claim that powerful factions within the MoH prompted this move, which in effect put NAS, and so GF resources, into their own realm of control. The move, bizarrely, meant that NAS as the Principle Recipient of the Global Fund Grant – Round Three running until 2009 – was now subordinate to sub-recipients in the MoH. Although those involved in the treatment

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[39] **'**Ahmadinejad arrives in Gambia' 23 November 2009; accessed February 3rd, 2010;
http://www.islamidavet.com/english/tag/gambian-president-yahya-jammeh/

'Iran vs US' Daily Observer editorial 19 December 2007; accessed February 3rd, 2010;
http://observer.gm/africa/gambia/article/2007/12/19/iran-vs-us
'Gambia Calls for Expansion of Ties with Iran' 2006-12-04; accessed February 3rd, 2010;
http://english.farsnews.com/newstext.php?nn=8509130371
Interestingly at the time of the 'cure' Iran also announced a similar state sponsored treatment for HIV (Amon 2008). Television coverage observed through 2006-2007 reiterated these messages.
[40] Grants approved for the Gambia for HIV in Rounds 3 and 8, for Malaria Rounds 3, 6 and 9, and for TB Rounds 5 and 9. The total approved funding for the Gambia is currently $102,450,992; information available on the GF website, accessed February 3rd, 2010;
http://www.theglobalfund.org/programs/country/?lang=en&CountryId=GMB

programme, and others in organisations linked into Round Three, were well aware of these shifts and the potential repercussions from the Global Fund of such blatant flouting of the rules, others in the Gambia were less aware. These events took place in January 2007, at a time when simultaneously the president, with public backing from the Secretary of State for Health, Dr. Mbowe, and the MoH, announced that he had the cure for AIDS. The connection - both political-economic and symbolic - between such subordination of global funding mechanisms under elements of the state, and the simultaneous rise of an alternative paradigm backed by just those state elements, seems hard to escape.

The Global Fund reacted to the NAS situation, and sent representatives to discuss this issue with the president. One story which circulated recounted how the GF representative, when he went to statehouse to meet with the president, was refused an audience, so that Dr. Mbowe had to run up and down the stairs passing messages between them. Although it was clear that if the situation remained the same, and the Principal Recipient did not regain independence, the Global Fund would pull out of funding Round Three early, and so halt the treatment programme, the stalemate went on for some weeks. Only when the GF threatened also to pull out of all TB and Malaria programmes was NAS reinstated in its original position, and the head of the NACP moved over to take the top job. The 'independence' of NAS remains questionable however, as 'they are all [government] health people in there now.'

The recent history of the GF in the Gambia, in practice, thus reveals a struggle between a globalism in HIV funding pitched to include and meet the claims of civil society including support groups, and elements of the state that sought to control the process. In the context of the enormous funding flows available, the material dimensions of this struggle - the perceived AIDS gravy train - have tended to be at the forefront. Yet people living with HIV have felt powerless to influence these large scale political-economic machinations.

Recently, in response to the formation of GHIs and their dominance in international health funding and programming, questions have been raised about the ways in which this funding plays out on the ground – one of the ways in which this research is useful and timely. The experiences of people living with HIV attempting to navigate this

landscape – within the clinics and support groups – is described in the following chapters. This case is revealing as it illustrates both the power of these global ideas and discourses and the extent to which they are taken on and negotiated: in the president's intervention, and the subsequent negotiations within government – NAS and the Ministry of Health – and within the support groups. All of these actors had 'bought in' to the GF discourse, but many abandoned it in favour of the presidential one, as will be discussed further in the following chapters. Due to the power dynamics involved it is not possible to say that this was fully voluntary, but it illustrates the way in which people are able to move creatively through very different ideological landscapes.

This chapter sets out the ways in which the 'assemblage' of 'Global AIDS' is experienced in the Gambia. These discourses, practices and negotiations are experienced on a day-to-day basis by people living with HIV and those working around the issue in the country. One of the elements which each of the following chapters charts, is how the global reaches into the local and impacts upon people's lives. It is possible also in light of the machinations around GF funding within the country and various statements and speeches to interpret the president's 'cure' as related to these elements of the global assemblage and the power which they exert. Again the following chapters all look to how these competing discourses are both similarly – in content and effects – and differently experienced on the ground, by people living with HIV.

4.   Bodily Spaces

For people living with HIV the body is always with them – in a much more conscious way than for others, their physicality, and mortality, is considered all the time a 'natural symbol' mediating between the body-as-lived and the social expectations and pressures people feel (Scheper-Hughes and Lock 1987). The symptoms which some people[41] commonly report include: joint pain; chest pain; stomach pain and diarrhoea; vomiting; headaches; coughing and TB; skin rashes; itchy skin and ringworm; sores on the body, the mouth and genitals; STDs and irregular menses; infertility and miscarriage; loss of hair and also teeth; the body becomes thin, a loss of appetite, 'body weakness', 'loss of power', and 'laziness'.

These illness experiences correspond to the three bodies of Scheper-Hughes and Lock's analysis; as individualistic experiences of the "lived experience of the body-self", secondly as "the body in sickness offers a model of social disharmony, conflict, and disintegration" and thirdly, the "body politic, referring to the regulation, surveillance, and control of bodies…in sickness and other forms of deviance and human difference" (1987: 7-8). As outlined in chapter 2, there have been many re-theorisations and conceptions of the body since Scheper-Hughes and Lock's formulation (Csordas 1999; 2002). Although the "fragmentation and vulnerability" of these 'multiple selves' (Van Wolputte 2004; 262) is in some ways an device – separating out different elements of a unified, although multi-faceted whole – it corresponds here to the similarly artificial separation of 'spaces' through the chapters of this thesis.

Responses to the question, 'do people with HIV think more about their bodies?[42]' illustrate the links people make between these three spheres in their everyday lives and experiences;

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[41] People in the support groups who have HIV-1, dual infected or HIV-2 whose disease has progressed and is symptomatic are often tired, having slept badly, and uncomfortable – with any combination of the above maladies reminding them of their condition. Of course, this is not everyone – for those who are HIV-2+ there is less immediacy in their condition. However, the support groups are sites of shared experience, and the potential for illness, and certainly for finger pointing, is also shared.

[42] This was one of the final questions used in the body mapping section of the workshops run with support group members at the end of 2007.

Yes, if the body gets thin people talk about you.

<div align="right">Women's workshop, support group, December 2007</div>

Yes, not being able to do your work, in order to earn income

<div align="right">Women's workshop, support group, December 2007</div>

People feel uncomfortable about the situation in which they live

<div align="right">Women's workshop, support group, December 2007</div>

Yes, they think of their bodies because of their family and how to take care of them, you don't have anything and also if you [become sick] who is going to take care of them

<div align="right">Women's workshop, support group, November 2007</div>

Because people are pointing their fingers at you

<div align="right">Women's workshop, support group, December 2007</div>

You think of the family and whether you will live long or not

<div align="right">Women's workshop, support group, November 2007</div>

Yes, people pointing fingers

<div align="right">Women's workshop, support group, December 2007</div>

Yes, they think more about having good health, support and care for their families both physically, mentally, emotionally and most importantly is financially and morally

<div align="right">Men's workshop, support group October 2007</div>

Yes, they think more about their bodies, especially how to get cured and support their families at home. Because the sickness makes you weak and unable to do certain work physically to gain something to provide food and other support for the family. There is no support of that nature given to the people living with HIV in the Gambia, or maybe to very few so far

<div align="right">Men's workshop, support group, January 2008</div>

You think of dying. You think of your children and who is going to take care of them

<div align="right">Women's workshop, support group, December 2007</div>

Making sense of bodily experience – of sickness or the potential within yourself for serious illness, and death – is built on a set of implicit assumptions about these three spheres and the relations between them, reminiscent also of Martin's (1994) 'system collapse'. This chapter looks to examine the belief systems which people call upon in order to try to make sense of an HIV+ diagnosis within different, but co-existing, framings.

These sets of beliefs are each linked with particular sources of claimed authority around dealing with HIV; here I set out some of the ways in which these worlds coexist and collide for people engaged in seeking treatment.

In the Gambia, as elsewhere (Baer, 1995; Geissler et al 2000; Janzen, 1978; Scheid, 2002) therapeutic pluralism is the norm. People move between systems for different illnesses, or repeatedly to treat the same illness. The categories which they employ to do so may differ from those expected by biomedicine (Leach et al. 2008). Similarly the ways in which people judge which system, or which practitioner to be the best are based on a wide variety of different factors (Last & Chavunduka, 1986; Bledsoe & Goubaud, 1988; Fassin and Fassin 1986). Several sets of beliefs now co-exist and are commonly used in the Gambia: various strands of 'traditional', Islamic and biomedical treatments. These intersect and overlap in various ways, and in the sense people make of them. This chapter explores both the different worldviews within which these systems are set, and key ways in which these intersections and interpretations unfolded and shifted during the fieldwork period – a period seeing first the roll-out of biomedical treatments, and an effective de-pluralisation of treatment options for people living with HIV, and then the introduction of the president's programme.

The first section looks to what are popularly known as traditional[43] beliefs around health and healing, drawing on the views of healers and their patients. This section

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[43] The use of the term 'traditional' medicine is problematic, implying a timelessness and stasis in these practices in the Gambia. Yet this is of course a rich and shifting field, which takes in a wide variety of practices and practitioners, some of whom are represented in this chapter. I use 'traditional' as it used in translation in the Gambia. People speak of *morfin-jaara* [black people's medicine, Mandinka] in

includes a discussion of people's reflections on biomedical treatment, and how it relates to these beliefs. The second section, based on the views of people living with HIV, discusses the workings of different forms of medication within the body, and the body with these different systems. The third section introduces the presidential programme, and the claims he made of a 'cure' – and how these claims drew variously on aspects of biomedical, Islamic and traditional systems.

While it is never possible to extricate each of these bodies – individual, social, or political – from one another, this chapter focuses more on the 'lived-experience' and health choices, and less on the body-social in terms of family and kinship relations. In contrast, the following chapter seeks to situate people's experiences within these wider social fields.

4.1.   *Traditional and Islamic Medicine in the Gambia*

> What I do is to help people from any difficulty that comes across them. I am a traditional healer by profession. I cure people on stomach pain, general body pain and even also people with medicine to secure jobs. I cook medicine for people who had difficulty in child bearing. If you use the medicine according to how I tell you it will be effective.
> Traditional healer, Western Division, interview December 2007

The ways in which traditional medicinal practices are imagined in tandem with 'western' biomedical treatment and care available in the Gambia are complex. Here I examine some of the main ways in which people make treatment decisions. First I discuss the key precepts and practices of traditional and Islamic medicine, then how imaginations of HIV relate to these. Ideas of what is a 'medical' issue are much broader in traditional conceptions than they are in biomedicine. They take in wider social issues as both symptoms and causal agents. This highlights the deeply embedded nature of traditional healing, as the effectiveness of herbal, or other, remedies, is dependant on much more complex sets of circumstances than merely the contents of the remedy.

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opposition to *toubabo-jaara* [white people's medicine]. In English most people translate this to 'traditional medicine' or sometimes 'our' medicine. There is also a strong sense of history and values within people's discussion of using these treatments, as is discussed further below, which is evident through the use of this term.

While people in daily life can, without contradiction, pass between these differing worldviews, as outlined below, there are ways in which the rationale from one can cross into the other. Schumaker and Bond outline how in Zambia concepts of colour from traditional medicine affect ideas about ARVs, "suggesting possible 'meaning responses' that could affect treatment outcomes" (2008; 2126). People routinely make judgements based on their knowledge and experience of this dual system as to which is the best course of action for them or a family member in any given circumstance.

Throughout West Africa local systems of healing based on different herbal and religious foundations, and as a combination of the two, are very strong (Bledsoe and Goubaud 1988; Bledsoe and Robey 1986; Madge 1998; Kleinman 1978; Leach et al 2008; Fassin and Fassin 1986; Schumaker and Bond 2008). The types of healing that I have discussed with people (practitioners as well as community members, and users of such treatments) can be categorised within three main types, yet in practice these blend together and can be used by one practitioner.

Firstly and most commonly seen in the Gambia, is herbal healing using the roots, barks, and leaves of various plants. These are dried and crushed or ground to make into potions to be drunk or bathed in, or they can be placed on a fire to be 'smoked' or inhaled by the patient. Vendors selling medicinal plants are commonly seen in all marketplaces, and the uses of various leaves are well known to many.

> I gather them [plants for remedies] myself after going through the collection of them all and put at one place then ready to bring them all home with me inside a sack. I will then separate them according to their functions; those used for drinking from a white [clear plastic] bottle, those to take shower with, those used for smoking [burning on a fire to inhale the smoke]. They will be split into small pieces and the leaves will be wrapped as bundles to be put in a bucket of water for taking shower with for a period of time.
> Traditional healer, Western Division, December 2007

Second is 'Islamic' healing performed by *marabouts*, based on the Koran; on knowledge and faith in the Koran, but also literally the contents, the medicinal value of the words themselves dissolved in water in which to bathe or to drink, or placed inside leather amulets and worn about the body. Bledsoe and Robey (1986) describe these practices in the Mande region, and detail the ways in which healing links with

concepts of both Islam and witchcraft and secret societies; the use of language here adding to the magic in a situation of 'restricted literacy'. Those healers who use this method will commonly combine it with herbal remedies, or, in the case of the amulets, with other medicinal objects that are placed inside. It is commonly said in the Gambia that 'for everything in nature there is a cure in the Koran'. In this form of healing this precept is taken literally, and can also encompass the use of certain plants as remedies:

> All these problems have different trees that can cure them… each tree existing has something to do and has a name and a verse in the Koran.
> Traditional healer, Western Division, February 2008

Third is divination: using cowry shells, beads, or other objects which are thrown and fall, or pouring water onto the ground from a calabash (gourd). While this can be used to tell the future or answer questions, it can also be used as a diagnostic tool.

> I use beads, and some the holy Koran [to diagnose]. I can give you one bead to personally recite or mention your concern or problems, which I will not hear, and later you will give me the bead. I will then mix the bead with others, about 7 in total, throw them on the ground and interpret the future. But I work more with herbs and roots more than using the holy Koran's verses.
> Traditional Healer Western Division, February 2008

> Some healers do not use these divining tools, but instead consider that "as soon as I see you, then I will know what medicines to prescribe"
> Traditional Healer Western Division, February 2008

> Those who normally use beads for diagnosing someone's problem are different with us. I use a calabash with some water inside to pour on the ground to read the signs and symptoms revealed. And it shows me the ways of treatment, if yes [possible], and the various charity to take out. This system of healing is by inheritance mostly [through family] but using beads are normally spiritual gifts from *jinni* [devils] or training.
> Traditional healer Western Division December 2007

The existence of *jinni* (devils or spirits – from the Arabic, used in Mandinka) is largely accepted as part of life. Those people who can speak to the *jinni*, or combat them, are seen to have special powers: of healing or divination, for good and for bad. In modern day Gambia there are many people who do not believe in these things,

saying that they are 'old beliefs' that exist now only 'in the village'. However, since no one is more than one step away from the village, and the ties of relatedness make sure that you always keep one foot there, perhaps no one – no matter how 'western educated' – completely puts aside these 'old' ideas.

Infertility is commonly associated with *jinnis* and possession by jealous spirits who will not allow their host to become pregnant. As female informants explained to me, those women who have many miscarriages or whose children die are also suspected of being possessed by jealous spirits[44] (see also Bledsoe 2002; Schaffer 2003). Women possessed by spirits are seen at funerals, and are an accepted part of the mourning procession in Jola communities. Rural communities in general and Jola communities in particular (generally in the Southern part of the Gambia bordering Senegalese Casamance) will talk about *jinnis* and spirits as a much more central part of life, and of illness and healing. Many people also travel to this area (Foni) in order to see famous healers – whether or not they are Jola themselves. Jolas are generally regarded as being the group that has the most power in this regard.

One perennial example of the belief in spirits is the appearance of *kankurran* – a forest spirit who collects initiates for circumcision and protects them from *bwa* [cannibal witches] while in the bush (Schaffer 2003; 181). In peri-urban Gambia the *kankurran* is a bogey-man; terrifying to children who believe that he can fly over their compound walls, as he arrives with an entourage of boys shaking his shaggy bark costume and clattering cutlasses together. During the months when initiates are taken to the bush he is a regular visitor. The entourage demand contributions in order to keep *kankurran* from harming you. Traditionally donations sustained initiates in the bush; now more commonly this is a fundraising activity that youth groups, football teams and even schools can engage in – often stopping traffic to demand coins – to supplement their incomes.

While *jinnis* are dangerous – as the spirits sent with sickness to another person – they can also be benign, and can bestow healing powers onto people. Many illnesses are

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[44] Also 'devil's lover' a short novel by Gambian author (Bojang 2007) on sale in supermarkets as a pamphlet – details the downfall of a young girl from a good family in Basse, and her decent into prostitution, all because she is loved by a devil

ascribed to witchcraft, including the much dreaded *bwa* or cannibal witches: those people who have secret evil powers and who wish to devour people. This notion embraces concepts of 'sent sickness', sometimes discussed in relation to HIV, or other unexplained illness such as epileptic fits. This area, of witches, devils and illness, is complex and shifting, and as Schaffer explains, the links between Islam and witchcraft are strong;

> Witchcraft beliefs prove the strength of Islam. Djinns lurk in mosques at night or are considered far more numerous in an especially holy village such as Karantaba. The other misconception is that witchcraft beliefs concentrate on *jinno*, *bwa* and *kumfanute* (djinns, cannibal witches and seers). These beliefs are quite complicated and have an almost infinite quality to them… 'Mandinka are a pile of secrets, some of which you will never learn.' Witchcraft seems to be an area where this limitation is especially true.
>
> Schaffer 2003; 182

Further ethnographies of groups in the Mande language speaking region of West Africa reiterate the importance of secrecy in establishing authority and legitimacy, linked to Islamic healing (Bledsoe and Robey 1986) and to the politics of secrecy in initiation societies (Bellman 1984) linked also to power and prestige (Murphy 1980).

4.1.1. Illness categories – treating HIV

"When a person is sick they are always eager to get well"

An elder, who took part in a focus group discussion on health and illness, used this saying to explain the motivation behind people habitually passing from one health system to another – between the clinic and the use of traditional healers. In daily life people do not strictly separate biomedical and traditional systems; of course they are separate geographically and conceptually, but to use both at once or in sequence for the same condition makes perfect sense. In fact many people faced with serious or chronic illness deal with it in exactly this way, trying all their options.

In essence HIV, as with any other sickness, can be understood and treated within these different belief systems. When people are first sick, they often turn first to traditional medicine; to counteract witchcraft if it is seen as a 'sent' sickness from someone wishing them ill. It is often difficult to resist the pressure from family to visit

a healer in these circumstances. One man who had been through this experience told me his story. He said that his mother had almost killed him taking him from one healer to the next, as the medicine used made him even weaker – but that he knew she did it because she thought it was the best thing. This man became a strong advocate for ARVs and the medical treatment that had saved his life.

Switching between seeking treatment through traditional or clinic based medicine can be based on bad experiences, of the treatment itself or the environment. One young man, who joined a focus group late, added at the end his story about having an ulcer. He went to the MRC, telling them he had stomach pain. But, he reported, they weren't interested, and forced him to do an HIV test. Later he found out he was negative, but he was never treated for his ulcer. Now, he said, he is on local treatment and he is much better. Many people relate similar stories and examples of the power of traditional healing in comparison with clinic-based medicine for a variety of illnesses and injuries.

Many people make a general separation between illnesses which are suitable for one kind of treatment or another. One common distinction is between those illnesses which are 'simple' and can be treated with herbs, and those which are 'difficult' or 'new' and for the clinic. This mirrors the findings of Leach *et al.* in Guinea concerning the distinction between 'clear' and 'obscure' illnesses (2008; 2162). However, different people – with different levels of faith or experience in either realm – would place different sicknesses along this spectrum.

> Some would say this, 'this is not a clinic problem to be treated but traditional healers', that is to use them to work evil things, or to change one's future. Either become mad or even lose your job and so on. People having 'epilepsy' are caused by evil spirits or *jinnis* [devils]. Those mostly are treated by traditional healers but not the clinic. And of course there are other problems taken by the doctors at the hospital, like blood transfusions and so on.
> Men's community focus group, Brikama, February 2008

Certainly in this description the hospital's share of tasks seems to me 'simpler' than these more supernatural maladies. However, witchcraft was often listed as an illness amenable to local healing, along with minor aches and pains, malaria, infertility and stomach problems.

Oh, I know something about traditional medicines, but they only treat headaches, evil spirits, stomach ache and joint pains but I do not think they can treat the illnesses we have discussed today [diabetes, TB and HIV]. I know that they are roots and bark of trees and that we see our parents and grandparents use them quite often. They use this for stomachache, headache and evil spirits at night.

Young men's community focus group, Brikama, September 2006

As with this young man there is a sense in peri-urban Gambia of the loss of traditional knowledge and practices. People variously express this in terms of the skills not being passed on, knowledge of the dosage or the correct treatment being lost, and also a sense of the breakdown of traditional values:

Some people also said it is because of modern life system leaving our traditions and cultures. There were traditional medicines that can be used to treat these problems by using herbs. I have fungal nail infections even now, and it has caused me to change my eating and my attitudes because I am not eating oil and benachin…

It is difficult to treat [illnesses with traditional medicine] and may take a long period of treatment, depending on the knowledge or on his or her way of treatment to be able to prescribe the right medicines to use. [The healer] may not know the best medicinal tree for that particular problem.

Mens community group Western Division, February 2008

Most people move successfully between systems, resorting to one when another fails, and seeking the most suitable treatment for their malady. When discussing why people would turn to a traditional practitioner rather than the clinic for different conditions many people discussed the loss of this knowledge in the community, and that the dosage was difficult to judge. Another complaint was of the healer being too self interested, and after financial gain, rather than working for the community, although some could see the necessity for such healers to also make a living;

If someone is in this situation [sick] you must be affected because of you have a human mind, sympathy and feelings and know that this person has sickness and pain and it is natural to both of us by God, you must feel affected of course, for that person to become better. But now, this money has caused many problems and difficulties amongst ourselves. Because even if I can treat [an illness] but would like to make a price of the cost of a bag of rice for my family's consumption first out of that, so then without pay you will not [get]

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help, and of course my cost of candles to use in the household and so on from this profession as a trade instead of support or help as expected by you. You can even treat that person until after [they are] cured, the person can pay according to agreements, in the best helpful way as accepted by God, who says 'help you neighbours and friends if they are suffering'.

Mens community group Western Division, February 2008

Both of these medical systems are equally familiar to Gambians in urban areas, and the decisions around which to consult, while individual, are based on familiar patterns of what should be treated in different ways, personal experiences and those of others.

The illnesses that are severe are HIV and TB. I am always worried about people who treat TB locally for a long time, but have not improved, then later they die. I know someone who had TB and was taken to the MRC for treatment and was cured.

The only way to treat these illnesses is through the hospital. No, traditional medicines cannot treat HIV, diabetes, or even TB. The only illness I know that is treated by local herbs is the illness *kulufentenngo* [rheumatism/yaws]. Treatment duration depends on the effectiveness of the medicines, sometimes it takes a long time… It is difficult to treat most illnesses, it may go for six months or more, to treat for two years.

I know of traditional healers, especially Jolas, who can treat most illnesses. One man came from Mali who cures Asthma.

Yes, we have traditional healers around and they can cure some illnesses like headaches and evil spirits… some traditional healers also help women who have difficulty in getting children…

Women's community focus group Brikama October 2006

With regard to the treatment of HIV, through discussions and focus groups throughout 2006 this was considered very much a disease 'for the clinic'. How this association has come about and been maintained will be discussed in more detail the following chapters looking at the 'clinical spaces' and also the support societies, as important loci within which such discursive expectations became established. From the examination of the 'global space' experienced in the Gambia, in the previous chapter, it is also possible to see the power of IEC campaigns of billboards, TV and radio adverts and community sensitizations in this regard.

4.1.2. Shifting beliefs about HIV treatment

However, after the president announced his 'cure' for HIV this situation changed. People – observed in my home and community, in the community focus groups and in the support groups - began to speak more often about the potential to use traditional medicine to treat HIV. This may be because while people had always thought it amenable to such treatment, they knew from health education messages that the 'correct' answer was that this is a disease for the clinic.

> Yes! There are many local herbs [to treat HIV] and the modern methods by ARV medicines which help to fight these HIV viruses to reduce their strength and control side-effects. But the treatment is like *patoo* in Mandinka which means treatment without complete cure, so it is said to be a killer disease leading towards death…
> Men's community focus group Brikama February 2008

The staff in the clinics discuss the difficulty of translating how ARVs treat but don't cure into local language and idiom. This is a problem of conception- that medicines should rid the body of disease, no matter how long this takes. ARVs only 'hold' the virus.

> Fungal nail infections, hernia and HIV [are the most severe illnesses in the Gambia] at the first time, but now our president is treating it with herbs. You know this HIV has been existing here between men and women for a very long time and was called in Mandinka *tong-tong kulongo* [taboo-taboo illness] another infection could also be contracted between a man and a woman through sex and is *keesanto* [syphilis] but could also be treated by using herbs.
> Men's community focus group Brikama February 2008

In this description this man is re-positioning HIV as an 'old' illness, and so amenable to traditional treatment. Before the president began his treatment none of the community focus groups discussed HIV in this way. Certainly while many people living with HIV did seek traditional remedies, this was often before they had a diagnosis and were trying to deal with long periods of unexplained illness.

> I was first ill and went to MRC, then I went to local treatment, then I went to private clinics, then from then I went to RVTH. I was always unwell. I had health problems like malaria, skin rashes, and vaginal problems. I was receiving medical treatment, and I was also using traditional medicines. I used

traditional treatment when I was in …village. I have used more medical than traditional treatment. Traditional treatment worked, but just for a short time. ARVs help me most… But I take a lot of pills, and they give me body changes and they make me feel uneasy.

HIV+ woman, not group member, interview in clinic, September 2006

I did the HIV test because my friend advised me, she was also HIV but didn't tell me that she was. I was having problems like headache and my legs were paining me, and I was happy that I did the test….
I used to go for local treatment and marabout. One marabout charged me 5000D [approx £100[45]] but I did not see my health getting better…
Now I am much better because I have vitamins and septrin to take. I went on Monday [to the clinic], and I was tested then the next day, Tuesday, I had my results. I was happy because I used to pay a lot of money to marabout….
I would advise people to stick to their medicines.

HIV+ woman, not taking ARVs, group member, interview September 2006

I was sick, then I went to RVTH but it was not getting better. Then my son took me to [town] and I paid about 3000D [approx £60]. Then I did not get better, then I decided to go to MRC for treatment. Then from there I had the test, I had the test so that I should know my status. When I was told about this I cried bitterly, and Dr … told me that there is a support group….
I do not take traditional medicines now.

Elderly HIV+ woman, support group member, not taking ARVs, interview October 2006

Throughout all the interviews with people living with HIV in 2006 there were many such stories; of the failure and expense of traditional medicine. These were all, as above, framed for me as transgressions. As I discuss further in the chapter on 'clinical spaces', health workers put across a very strong message that treatments should not be mixed. However, while medical staff were aware of such mixing of treatments it was not openly discussed. For example, one woman on ARVs was admitted into hospital severely malnourished. When I visited her, the staff concerned muttered that she must have taken traditional treatments, which had purged her system, causing extreme weight loss and her ARVs to be 'lost', but she denied this. While many people in the support groups would talk about their past transgressions, and those of other people, they were very keen to stress that they were 'with the clinic now'. However, informal

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[45] Here I give approximate equivalent values in pounds, however, a better way of understanding the extraordinary expense these people went to is that a sack of rice cost around 500 Dalasi, more than a teacher would earn in a month. For these people with little and irregular cash income, particularly women, such large amounts could only be raised with great difficulty, often from family members.

conversations and gossip between people tells a different story, people did visit other healers, for themselves and their children.

4.2.   Traditional Healing – authority and connectedness

This section looks at the ways in which traditional healers are legitimised; the authority they build their practice upon. While all elements of such a complex system cannot be considered here, I focus on those elements which are useful in understanding, in the following section, the president's processes and bases for his 'cure'.

Traditional healers all spoke about the specific ways of collecting plants from the forest, and the importance of maintaining the traditional ways. Such explanations are a claim to legitimacy, constructing healers as the possessors of secret and magical knowledge and also as authoritative members of the community, continuing traditional ways which would otherwise be forgotten.

> In the process of collecting or fetching the medicinal trees, herbs, and digging the roots, you also learn and see a lot. You also perform certain ceremonies traditionally and culturally in a form of greeting and asking permission to the spirits of the tree before, or else you may have a problem or being chased away by a big snake or another thing.
>
> Traditional healer Brikama December 2007

> I got them [medicinal plants] in the bush and sometimes in the forest but I must take along with me some tobacco leaves and the powdered one as well…
>
> This is because every tree existing has its own spirit living with it, and has its name and a way of greeting or ceremony to perform first… three times, and then place the tobacco leaves or pour the powder all around the tree before digging the roots or collecting the leaves. Some trees you must greet them by saying 'Asalaam alaykum - Nyass' [translation; peace be with you (universally used Arabic greeting) – expect/anticipate (me)] three times as well before doing anything…
>
> Sometimes [if you don't perform these greetings] you may find a very big snake or aggressive bees which will prevent you from collecting these ingredients for the medicines.
>
> Traditional Healer Western Division December 2007

Another healer/trader in medicines who had a regular market stall explained how to tell which greetings to give according to family relationships. Names in the Gambia show many things, and are a marker of relatedness. As described in the next chapter, the ways in which names can be used to smooth relationships and show either kinship or establish 'joking' relationships also applies to tree-spirits; for those with thorns choose a name with which you (the gatherer of the plant) have a joking relationship, so that you will not be harmed (traditional healer, Brikama, January 2007).

Another healer linked trees more strongly to a family of their own:

> The mother of a tree is the earth or soil, so you must know how to greet and what to perform as a way of asking permission to use the child for a purpose. Otherwise you will lose the medicinal value – after all, if you want to send someone's child to somewhere [on an errand] without asking permission from the mother, what would happen?
> Traditional healer, Brikama, February 2008

All of these precautions are important not only to enable the healer to gather the plants he needs, but also to preserve the medicinal properties of the plant. These are contingent on the gatherer's knowledge and ability to carry the treatments out, not merely the properties of the thing as taken by anyone who wishes to try. Without connectedness nothing works.

Family names also indicate those who are more likely to be healers – those connected to the traditional *marabout* skills of metal and leather working (Conrad and Frank 1995). Many traditional skills are hereditary, and healing is no different. Healers spoke of having a mentor, usually their father or grandfather, and also of going through a learning process and gaining knowledge as they practiced:

> I inherited this from my forefathers [who] were doing it for the past decades. It used to be done by turns until my father became one of them. When he died then I came to take over. This thing is in our family, it is a chain from one person to the other. I am the eldest son of my father this is why I took over. It is our culture. My job as a traditional healer is the same as what my forefathers used to do, we use the same materials for our jobs. I was trained by my father in order to deliver effectively. If he was to go to the bush to find herbs we would go together and he will show me everything. I have attended

> trainings from different health centres to know the linkages between western medicine and traditional medicine.
>
> <div align="right">Traditional Healer Western Division December 2007</div>

However, not all healers inherited their abilities from their lineage. Some were granted their powers through their prowess as hunters, through the knowledge they gained in travelling widely around the region, or in chance meetings with *jinni* who can grant such powers at will.

> This knowledge and profession as a traditional healer even my born father did not think of it either, but only God knew of it. Yes, although my father was a great traditional healer but I did not inherit it.
> *Q: you did not inherit this from your family?*
> Yes, I didn't because my father came to know about it through a surprise. I was not trained by someone or neither learnt it but had it through other links during my travelling because I have travelled to many different places in the sub-region, up to Mali.
> *Q: How did you come to be a traditional healer and what were your links?*
> Yes, this is a difficult question to answer directly. But I was given this knowledge through something… a jinni, and I am grateful that many people do come to me.
>
> <div align="right">Traditional healer Western Division February 2008</div>

It is clear from the above exchange that talk of *jinnis* is one of the more secret activities of healers and *Marabouts*. However, many were also very forthcoming, giving explanations which surprised my research assistants, who told me that they had never heard of these things before. These stories also included cross-over between the worlds of devils and magic and Islamic beliefs, as well as a stress upon the importance and power of concealed knowledge.

4.2.1. What constitutes a problem? – Values and reciprocity

I would like to tell you one story of someone who came to me for wanting to travel to Europe, and had been trying several times without success. He came to me and I told him that if I work for you in between three to four weeks you will have your papers and leave the country. But he could not believe, because he had been to many marabouts and traditional healers who cannot help.

Since I have agreed with this man on how much to pay me for the job and I went to the bush to find this medicine and also asked him to take out certain things as charity first.

Then I gave him my medicines to use, some to take showers with and some to drink for a period of two weeks.

Finally between the end of the fourth week I was told by his brother he went to Germany.

I first of all did perform some miracle by taking a blank white paper, nothing written on it, and put it inside water in a bowl then burnt the paper whilst inside water. After the whole paper was burnt to ashes, I put my hand inside the bowl and took out a juju which I gave to him to tie on his waist. This verse in the Koran is also in the Bible, even Christians know it. But I don't do it to many people because I am alone, I have no child of my own to inherit my skills. I have adopted my brother's daughter who is with me at home.

<div align="right">

Traditional Healer Western Division, February 2008

</div>

The story above illustrates some interesting aspects of traditional healing in the Gambia. Firstly, the 'patient' is not ill, but wants some change in his life, which he feels a *marabout* can assist him with, despite repeatedly trying this route already with no success. All of the people that I interviewed – clients and healers – listed such items as 'witchcraft' and 'lack of a job' mixed in with 'stomach pains', 'general body pains' and more chronic illnesses such as diabetes and asthma.

The story also illustrates the value of payment, both to the healer and in charity, which as part of the bargain is just as important as the miracle later performed[46]. Here he shows the mixture of methods routinely used in treatment, the religious-mystical combined with herbal remedies and different methods of consumption of these. The final part of the story hints at the importance of connectedness: as the healer says, 'I

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[46] People routinely wait by Mosques in order to receive charity; it is one of the pillars of Islam to give a certain amount of your income to the less fortunate, so those who can give do so to those who wait, as well as those instructed by healers.

am alone', and so his skills will not be passed on, but he also sees little point in building a reputation for this – if widely known – highly desirable skill. Another aspect shown here is the concept of community recognition, and building legitimacy as a healer, based on reports from past customers, their families and so on. As Fassin and Fassin (1986) show in Senegal – where the same systems exist – the reputation and legitimacy of a healer is largely based on word of mouth, and it is less successful healers, those without regular clients or a family history to legitimate them who make reference to more official regulation or associations in order to manufacture a reputation.

There are traditional healers in every community, and every village has at least one. All of the community groups that I conducted discussions with talked about one or two individuals – both herbalists and religious healers – in their locality. These healers are very much part of the community, giving support as much as treatment:

> They [traditional healers] should do something to help them [people affected by illness] by counselling them to keep faith in God, also treat in their traditional ways in providing and giving them herbs, roots, charms, *jujus* [charms] to protect from evil spirits so that they can be cured, at anytime needed.
>
> Men's community focus group, Western Division, February 2008

The effectiveness of the medicine also depends upon reciprocal and community arrangements.

> Any time you are sick and take my medicine it becomes effective depending that you take the dose according to how I told you and if you have the belief. The effectiveness also depends on the way you charge. If it supposed to be 5 dalasis stop [only], don't charge beyond expected price because that's the agreement between me and the jinnis who gave me this knowledge. There are some illnesses that you only pay tobacco leaf and a chicken, no money, and it will be effective.
>
> Traditional Healer Western Division, February 2008

The monetary exchange is important, and it is vital both that the patient pays the desired amount, and also that the healer does not over charge. The price of seeking the help of traditional healers is much higher than the charges at the clinic, and even of drugs (when they are available). For people living with HIV, clinic visits and drugs

are free, and even transport fees are refunded. Many people said that the charges for traditional healing were too high – and some that they had gone up. It is difficult to know who is a 'good' healer, and who is not, except by local reputation. An unknown healer may overcharge for ineffective medicine.

A second reason given for mistrust or uneasiness around the effectiveness of traditional medicine is due to the problem of dosages. The group of elders who took part in the focus group quoted below said that 'we are all practitioners ourselves' and stated a strong belief in traditional medicine. However, the correct dose for any treatment was difficult to know, and in many cases was 'lost'.

> The methods of treating them [people with illnesses] would be at hospital but some others recommend local treatment. But I believe very much in the local way. Even now this AIDS, researchers are looking for this through local and modern medicines. For us old men we really believe in traditional medicines and most of us here are healers. Traditional medicines can cure some of these illnesses, it is only that we don't know the doses. So it disturbs us because we don't measure the quantity, we just drink. And hygiene is also important, we do consider most of these things, because traditional healers have never been to school.
>
> Older men community focus group 2006

4.3. Medicines in the body

Looking at these very contradictory and yet interlinked systems and discourses around HIV and treatment, the following sections aim to extricate the 'sense' which people living with HIV can make from this.

The strongest idiom which people living with HIV use to describe their condition is that of the immune system – 'body soldiers';

> HIV fights body soldiers and it enters the white blood vessel. That's where HIV stays, it circulates through the body.
>
> HIV+ woman, women's workshop, support group, December 2007

> HIV is a virus that stays in the blood and destroys the body soldiers.
>
> HIV+ woman, women's workshop, support group, December 2007

> HIV destroys the body soldiers.

[With HIV] the body becomes lazy, it follows the body soldiers.

HIV+ woman, women's workshop, support group, January 2008

This military imagery is reminiscent of Sontag's (1991) discussion of the images and metaphors used to visualise disease. Martin (1994) suggested that such immune system thinking and imagery is a particular western cultural discourse dating back to specific circumstances in the 50s. As Kirmayer notes "the explicit notion of the immune system discriminating between the self and non-self has been the dominant metaphor in immunology since Macfarlane Burnet's seminal work in 1949" (2003; 284). That Gambians should be using such similar imagery to represent their immune systems and the 'invading' virus raises questions about the ways in which such idioms may be passed through clinical interactions, and the ways in which clinical relationships mediate the sense people come to make of their condition. These questions will be discussed further in chapter six, where I explore clinical spaces. Certainly the agency ascribed to this 'foreign body' within the body can be seen in many of the ways in which people describe HIV;

HIV holds the muscles and the veins.

HIV makes the body weak

HIV kills the heart

HIV stays in the body

If you have TB together with this HIV it kills easily

HIV+ women, women's workshop, support group, December 2007

The individual body is a creation of biomedical science. In the latter, the individual is the subject and appropriate target for medical interventions, in contrast with a broader focus on the social issues which create the conditions for illness and disease (Farmer 2000; Fassin 2007; Labonte and Schrecker 2007).

People living with HIV describe and understand their condition using the metaphors which are produced around and from them, but these are not necessarily satisfactory.

While military metaphors which describe the action of the virus within the body are frequently used they do not adequately describe the experience of being HIV+ in such an interconnected society. This sense of connectedness again draws parallels with Martin's recent, American 'flexible bodies' model;

> The 'body at war' can re-emerge even in the midst of a prevailing complex systems model that constantly erodes the significance of body borders and emphasises the interconnection of everything.
>
> <div align="right">Martin 1994; 136</div>

If Gambians see things this way, this might suggest a universalism. However, in relation to the connectedness of existing traditional modes of treatment in the Gambia this implies a particular but perhaps different Gambian understanding of interconnectedness.

Thus, people living with HIV in the Gambia, in a similar way to the people analysed by Martin, operate within a dual frame – that of the individualised body and conversely, the interconnection of everything. This opens questions of control, agency and blame. Where external circumstances have unpredictable effects, the individual cannot be blamed for succumbing to circumstance. On the other hand, the cult of blaming the victim – for not taking sufficient precautions, for failing to follow official advice – is compelling, with the individual as deviant. People often state that 'I did not buy this [HIV] in the market' – that is it was not an active choice to become infected. The effects also spread far beyond the individual medicalised body, taking in social relations and the ways they are shaped by this diagnosis. These issues are taken up in the following section, as well as in the following chapters.

In interviews I also encountered descriptions of 'the diminutive foreigner' with a 'science fiction flavour' (Sontag 1991) with the ever present CD4 counts and viral loads as familiar markers and descriptors of the individual body under attack:

> [CD4 counts] are the human body soldiers that fight against infections, or called white blood cells
>
> <div align="right">HIV+ man, men's workshop, support group, December 2007</div>

[A CD4 count] is how many body soldiers are in your body.
> HIV+ woman, women's workshop, support group, December 2007

[Viral load is] the number of viruses in your body, and whether it is going up or down.
> HIV+ woman, women's workshop, support group, December 2007

[Viral load] is the amount of viruses and loads detected in the body or system
> HIV+ man, men's workshop, support group, January 2008

[Viral load] is the criminals that come to attack the white blood cells and weakens them.
> HIV+ woman, women's workshop, support group, January 2008

People use the systems and metaphors that are available to them, through familiar systems and signs. The quotes above are all from people who identified themselves as 'with the clinic'. This demonstrates the ubiquity of the biomedical model as the dominant frame through which to understand this infection. This is not the only model, as demonstrated above, but its ubiquity shows the extent to which people apparently accept the dominant discourse rather than these other frames.

4.3.1. Taking treatment

I turn now to understandings of HIV treatment, first ARVs and then also the presidential 'cure'. When it comes to the question of ARVs the classifications – as ways to make sense of illness and treatment – fit the same pattern. People demonstrate a good understanding of the ARV treatment system as defined by biomedicine. This is, arguably, a positive effect of counselling and enables people to understand their treatment regime and the importance of adherence.

It [ARVs] goes straight to the stomach and then to the chest or heart where it joins the blood circulation….

Medicines help to increase the power or strength of the white blood cells, CD4 count, to fight against the virus and decrease the viral load.
> HIV+ man, men's workshop, support group, December 2007

ARV flush the virus, if somebody stops taking ARV the virus destroys the white blood cells and you die quickly.

> ARVs goes to the stomach from the mouth then goes to the heart to mix with the blood to the muscles and circulates in the body.

> It [ARVs] affects the whole body; vomiting, diarrhoea, persistent headache, tiredness, dizziness and sometimes skin rashes. But this also depends on the patient's nature. It also causes hunger and is like an appetiser so you must need strong and nutritious food.
> HIV+ man, men's workshop, support group, December 2007

The side-effects, as above, and the difficulties which people experience with these strong and toxic drugs are stressed throughout. The desire for food – that ARVs give appetite – is particularly poignant for these people;

> Most important is the lack of food and nutrition because these drugs or medicines [ARVs] are very powerful when you take them and require food. They cause serious hunger soon after taking them and could make you collapse without food to eat. Now what about if you are very poor, like myself and others, and it is time to take them, you will fear taking them.
> HIV+ man, men's workshop, support group, January 2008

Thus, although the individual body is considered, and the action of these specific medications within it, it is within the social and political spheres that the experience of illness also expresses itself; in terms of poverty and lack, and in expectations of assistance. These themes will be taken up again in the following chapters, as they emerge within domestic spaces and support groups.

ARVs are universally seen to be in the blood, and circulating around the body, as with HIV. Many people are able to give an approximation of the way in which they work with the 'body soldiers'. Others also have a sense of the drugs halting the progress of disease:

> [ARV] is a drug that helps to maintain the virus at one place.
> HIV+ woman, women's workshop, support group, January 2008

People are also able to understand the sense, if not the detail, of the numbers they so often hear;

> [CD4 is] body soldiers, if it gets down it means the soldiers are not strong and lazy but if it gets high that's good.
>> HIV+ woman, women's workshop, support group, January 2008

One disparity between the responses of the groups was in the discussion and comparison of the workings of traditional herbal medicine with ARVs. The power of 'western' drugs was discussed by all:

> With western medicine or drugs if you drink even paracetamol it will hold the disease.
>> HIV+ woman, women's workshop, support group, January 2008

However, while all three male discussion groups[47] stated very strongly that;

> Herbal medicines work in the same way as the conventional medicines.
>> HIV+ man, men's workshop, support group, December 2007

> Herbal medicines also work in the same way as the ARVs through the blood circulation
>> HIV+ man, men's workshop, support group, December 2007

> The ARV medicines work in or through the blood circulation system.

> The herbal medicines also work in the blood circulation in the human body, as the ARV drugs do in the same way.
>> HIV+ man, men's workshop, support group, January 2008

The women's discussion groups (80 women in eight groups, two from each of four support societies) all firmly put forward the opposite idea;

> Herbal and western [*morfin-boro aning toubab-boro…* black people's medicine and white people's medicine] don't work in the same way. There is some small difference.

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[47] The disparity between the numbers; 28 men in total and 80 women, is representative of the demographics of the groups themselves. One group was the total of the male members from two support groups joined together; the others struggled to make up one group each (three male workshops for four support societies). Each of the support groups easily recruited two groups of women, and some may have been able to bring another together.

The disease that is supposed to be treated by herbal medicine if you drink western medicine it will not treat [work]. Diseases that are to be treated by western medicine if you drink herbal it will not treat.

If you drink herbal medicine it goes straight to the stomach with full force and gathers the disease together, that leads to diarrhoea, vomiting and laziness.
HIV+ woman, women's workshop, support group, December 2007

If you drink herbal medicine it goes with full force. It can cause stomach pain, diarrhoea, and it spreads instantly. It causes dizziness because it doesn't have a specific dose. This is why it is powerful compared to the ARV medicine, it has a dose and if you drink it goes slowly – slowly from the head to the general body.

Traditional herbs wash the stomach and clean the dirt.
HIV+ woman, women's workshop, support group, December 2007

That this distinction should be made so clearly along gender lines is interesting. It suggests to me that men espouse a more 'scientific' or 'educated' view. This could imply that they understand and process more of the scientific, biomedical precepts and are thus more inclined to abandon more traditional concepts of medicine staying in the stomach. However, it is also possible, similarly to observations from Bledsoe and Robey (1986), that 'white people's' knowledge is associated with 'modern' behaviour and achievements, and is open; whereas, local and Islamic knowledge is equally powerful, but secret. Here, perhaps my positionality, as a foreigner with perceived links to biomedical treatment, and a woman, also explains this gendered difference in people's explanations.

Cleaning the stomach - the purgative effects of traditional healing in restoring purity and cleanliness to a "dirty stomach" - is the most common way to explain the functioning of traditional medicines. In this they can be very powerful, related again to the difficulty in assessing the correct dosages. Certainly the presidential 'cure' was experienced in this way:

Herbal medicines also work in the same ways as ARVs, but with herbal medicines the vomiting and diarrhoea becomes worst. In that case you feel more dizziness, loss of appetite and even loss of weight, severe cramps and joint pains. One day we drank the president's herbal medicine with some other women but that day everyone was very dizzy and it is like we were drunk. We had very severe diarrhoea and even the women suffered a lot by frequently

passing stools or diarrhoea. That medicine was later called *jinna* meaning devil, because of its side-effects.

<div align="right">HIV+ man, men's workshop, support group, December 2007</div>

The variability of traditional medicines, including the president's, is also clear here, as on that day the medicine produced these effects, whereas on another they might have been less.

The side effects of traditional medicines in general are serious, and they cause discomfort;

If you drink [traditional medicine] you get dizzy, diarrhoea, stomach pain. It doesn't work the same way [as ARVs].

<div align="right">HIV+ woman, women's workshop, support group, December 2007</div>

These women listed many properties for traditional medicine, including some negative side effects, but others related to its positive effects; that you should suffer to be well is part of the healing process;

It has no measurement [dosage]
It makes diarrhoea
You vomit
It stays in the stomach to wash the dirty things from the body
It causes frequent urination
It can treat *seketo* [genital warts]

<div align="right">HIV+ women, women's workshop, support group, December 2007</div>

Only one group stressed an opposition to the use of traditional medicines for HIV;

Some [of us] have never tried to take traditional medicine.

[Traditional medicine] hides the infection.

<div align="right">HIV+ woman, women's workshop, support group, January 2008</div>

At the time of these workshops, almost a year after the president had made his announcement of a 'cure', it is evident that a re-pluralized debate had emerged about the relative merits of different medicines and different medical systems in treating HIV. As discussed earlier, prior to this, in 2006, no such debate was taking place, and

at least in public, HIV treatment was generally seen unequivocally as a biomedical, clinic matter. The support groups were sites where the biomedical discourses inscribed onto these people's bodies were enacted. As explored further in chapter six, they are sites where people are most strongly connected to the bio-medically informed and dominant discourse of 'Global AIDS' and clinic-based ARV treatment. In 2006 most people living with HIV strongly denied taking traditional medicines themselves or currently. As one woman explained;

> I am using medical treatments, but not herbal medicine. I have never stopped [taking ARVs] because I know that is why I am still alive. I have not used local medicines because we have been advised not to use local herbs. My health is ok now, and people even admire me and are surprised, because the women that I'm staying with thought that I would never get well.
> Female HIV+ on ARVs, interview, support group, September 2006

Thus throughout 2006, the 'Global AIDS' discourse was actively taken on and engaged with. Many people spoke about their experiences with ARVs with images of a dramatic return to health made possible through treatment, echoing findings elsewhere (Robins 2006; Farmer 2000). These images are also resonant with ideas of 'therapeutic citizenship', which I return to in the final chapter on support societies (Nguyen 2005; Rose and Novas 2005).

However, perhaps the hold of this discourse over those enacting it was rather weaker than was thought, or than it might seem from statements such as this. This woman, among many others, chose to enter the president's care and stopped taking her ARVs. She was later discharged but never returned to the support group, and I last heard that she had become very ill. It is striking in this context that the president's 'cure' so easily reopened a plural field of health options for people to navigate – or overt discussion of them.

4.3.2. Bodily experience and appearance – 'people do point'

> There was a change [in my relationships] in the sense that I was suffering from sickness. Apart from being sick, things were normal with me and my family.
> HIV+ woman, not support group member, discussing her situation before diagnosis, interview in clinic October 2006

The experience of illness is a process of enactment; the body as one's 'social skin' (Schepher-Hughes and Lock 1981) provides a potentially visible map of symptoms and signs to others, and creates feelings of insecurity, around protecting and hiding the truth. Following Goffman's (1963) notion of 'spoiled identities' it is possible to trace the roots of stigma, and of self-stigma and self-controlling and restricting behaviour, to these fears. The following chapter takes up these themes in the context of family and social relationships and expectations. People living with HIV are very conscious of the ways in which their bodies could give away their condition to others around them, that the body could disclose, returning to ideas around the 'agency' afforded to the body or sub-personal elements of the body (Kirmayer 2003).

The biomedical stress on the individual, and therefore on individualised responsibility, places people within a structure of 'rights and responsibilities' for their biological and social selves. Although this discourse of rights can be empowering, it fits badly with a therapeutic landscape in which illness and treatment, as in so many contexts, are not individual affairs (Janzen 1978; Kleinman 1980; Bossart 2002).

As will be elaborated in the next chapter, the individual body seeking treatment does not correspond well to this context, where there is rarely a treatment dyad between the patient and the healer but instead a wider set of considerations mediated by family and society. In this way the much more embedded traditional schemes of healing and treating are more comfortable. For example the concept of illness coming from outside (sent sicknesses, *bwa* and so on), not from the individual, symbolising a 'chaotic' system collapse (Martin 1994). In traditional ideas of illnesses, and communication about illness, people are linked into community and connectedness as in other forms of traditional healing (Geurts 2002).

Appearance is all important in the Gambia. To be well dressed and maintain your appearance is a vital part of being in the community, for women especially. Keeping this going in conditions of chronic ill-health and poverty can be draining, of both resources and spirit;

> I could recall before I became infected I was healthy and a good looking body but when my status was known my economic [situation] was reduced, my

body became thin and I don't go out in public because if I put on clothes I don't feel satisfied.

I think about how I was before and now, [they] are different. In addition the expense becomes higher just to have good health.

> HIV+ woman, women's workshop, support group, December 2007

For many people, the trade-off between food, to gain health and strength, and other expenses and uses of their time is difficult (Bourdieu 1985; Meinert 2004). ARVs form an important part of this, as those who take them demonstrate their restorative power;

> It is very important, since I started drinking ARV drugs I feel ok and I feel healthy.
>
> HIV+ woman, women's workshop, support group, December 2007

There are many ways in which these beliefs and discourses act upon or are made visible through the body and bodily experience. Understandings of health and healing can give hope, or conversely despair. As with the confusion around cure and treatment, HIV care is fraught with misunderstandings and disappointments, which can be changed by language and explanation;

> I was very much discouraged because at MRC I was told that it cannot be cured at all. I was told at RVTH that I will feel much better.
>
> HIV+ man, interview in support group, November 2006

ARVs are almost as difficult, in terms of side-effects, as the disease itself;

> Since I started drinking the drug I felt sick again. It seems as you take hot water and pour it on my body.
>
> HIV+ woman, women's workshop, support group December 2007

Through the experience of taking ARVs, the physical effects, the meanings and interpretations attached to them, and the biomedical environments and ideology they are part of, people make sense of their illness and treatment. The following section looks to the president's 'cure', and looks to find the commonalities as well as the striking differences in the understandings of HIV and its treatment as portrayed through these new relations.

4.4. The Presidential 'breakthrough'

> I am not a witch doctor and in fact you cannot have a witch doctor. You are either a witch or a doctor… I can treat asthma and HIV/Aids and the cure is a day's treatment. Within three days the person should be tested again and I can tell you that he/she will be negative….. I will not treat anybody who is not diagnosed as asthmatic or a HIV/Aids patient by a doctor…. I am not doing it for money or popularity. The mandate I have is that HIV/Aids cases can be treated on Thursdays…[48]

The president's announcement of his 'cure' programme – the 'breakthrough' as it came to be known – was based upon a mixture of justifications ranging from those borrowed from biomedicine, to those invoking Islam and traditional healing. Through his own speeches and the constant coverage and congratulations in the media, as well as the experiences of some of those 'cured', it is possible to look to these foundations to try to decipher, if not the motivations, then at least the apparent functions of this bizarre chain of events. Notably, all of the president's patients went voluntarily to be 'cured'. Their decisions to enter the programme related to the presentation of the 'breakthrough' itself, and the beliefs it tapped into in order to recruit fearful, and hopeful, people.

It has never been made explicit from whom the President's mandate to cure came, although supportive commentators have called it a 'gift from Allah'[49]. The remedy consists of 'seven herbs named in the Koran' in the form of bodily washes and a drink, to be administered by the president himself or a nominated assistant through procedures bound with secrecy and intricate rules.

All patients taking ARV treatment under the president's programme were required to cease treatment, among other strict dietary and personal constraints, on the grounds that this would interfere with the herbal/koranic cure.[50] This directly echoes the demands of clinic-based ARV treatment (in that case, to cease traditional medicine) and sets up a similar dilemma for patients. In this case however, patients were confined to a hospital. Over time – as the president became more paranoid about outside interference – they became more isolated and confined, with security

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[48] http://www.statehouse.gm/pres-rvth-board_170107.htm, presidential statement, May 2007.
[49] http://www.statehouse.gm/hiv-editorial.htm
[50] http://www.statehouse.gm/hiv-batch3_170407.htm

personnel in control of visitors and home visits, in these circumstances no 'transgressions' were possible.

The president now has other treatments for his people include those for infertility, hypertension and diabetes among other ailments (Amon 2008, Cassidy and Leach 2009a). The president's speech at the three year anniversary of the 'breakthrough' promised "eight new discoveries"[51]. At the start of his programme all 'western' medicines were claimed to be incompatible with his AIDS 'cure'. As time went on, however, this restriction was quietly lifted and people who became sick were transferred to the national hospital, receiving any medication available – except ARVs.

The Gambia's political context is dominated by president Yahya Jammeh, and his often shocking statements and actions. His ever-expanding treatment programme for a variety of illnesses stands out amongst these. In 2008 the president threatened to behead homosexuals, and several people have been arrested. He also sent his personal militia – the 'green boys' – with traditional healers to seek out witches in his home region; hundreds of people were rounded up[2]. This witch-hunt in particular has resonances with some of my final observations in the Gambia, in early 2008. Watching television with one of the 'cured' we saw him casting out *jinni* from a woman who had come to be cured of infertility. This was the beginning of a period in which the president became much more 'traditional'. Journalists, opposition politicians and others are imprisoned for criticising the government. In this context social or political activism and even political opposition is severely constrained. For people living with HIV it is impossible to dare to contradict the president.

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[51] "In his keynote address, President Yahya Jammeh announced his discovery of the Herbal Therapy for patients with stroke, sickle cell, diabetes, and arthritis, saying he had been successfully treating patients with such diseases. He assured those already suffering from stroke and are paralyzed to come forward and benefit from his treatment. President Jammeh disclosed that his herbal medicine can prevent one from having a stroke in a situation where one is likely to have it…. In this regard, President Jammeh proclaimed that "by the grace of The Almighty Allah", the 4th anniversary celebration of the breakthrough in 2012 will witness the announcement of eight new discoveries. He commended beneficiaries of the PTP [presidential treatment programme], especially the first batch of HIV/AIDS for their trust and confidence in him and all those who in one way or another supported the treatment program." http://www.statehouse.gm/hiv-aids.htm

4.4.1. Systems of Justification

It is impossible to understand fully what led the Gambian president to undertake his 'cure' programme. Some commentators, particularly the predominantly web-based opposition media, have pointed to mental illness, considering the president to be deluded and irrational[52]. Equally, it is possible to point to Jammeh's apparently unshakeable belief in his personal powers and to the faith that he shows in his cure programme, his apparent unawareness of the deaths that have occurred, and the faction of people who support his medical programme absolutely; interpreting this unquestioning support as politically self-interested sycophantism.

While these personalised dimensions may be significant, however, they underplay important aspects of the political and institutional context of AIDS programming, and science more generally, in which Jammeh launched his programme, and in which its framings of AIDS make sense. The wider political aspects of this issue were introduced in the previous chapter, where I noted the extent to which the president has justified his programme with appeals to pan-African and pan-Islamic discourse. As discussed there, by 2007, global and intermediary organisations working in the Gambia were demonstrating their capacity to roll-out ARV treatment, setting up and reinforcing notions of the 'right' ways to understand and to programme for HIV treatment, prevention and care. In this context, it was suggested, the president's programme might be interpreted as a counter-response to the expanding power of western biomedicine. Yet this can be only part of the explanation. Here, I focus on the ways in which the president also appealed to local, Gambian ideas of healing and medicine in order to legitimate his claims.

The presidential treatment regime constructed and appealed to a notion of 'traditional' remedies as opposed to 'modern science'. Towards the end of 2007 – and notably at the (rather poorly attended) rally to mark the one year anniversary of his breakthrough - the president was hailed as the self-styled 'MMB': the Medical Myth Buster[53]. This

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[52] 'Inside The State House With Teeth Bite: Dr.Mbowe Says Jammeh Is Mad!' http://www.freedomnewspaper.com/Homepage/tabid/36/mid/367/newsid367/1488/Inside-The-State-House-With-Teeth-BiteDrMbowe-Says-Jammeh-Is-Mad/Default.aspx

[53] Pictures of the third anniversary procession on January 17th 2010 also show this slogan http://www.statehouse.gm/images/breakthrough-3rd-anniversary_170110/index1.htm

presidential ability to claim credibility as a 'traditional' healer was enhanced by - and in turn affirmed - his own claimed genealogy as a descendant of powerful traditional-healer ancestors. One of the justifying aspects of the treatment programme widely discussed in the Gambia, and referred to by the president and his supporters[54], was that the president's grandfather was a famous bone-setter. In political terms, the president's treatment with its 'mandate ordained by Allah' can also be read as an appeal to personal charismatic/religious power. While the significance of charismatic forms of legitimacy for traditional medicine have been recognized (Fassin and Fassin 1986; 353-357), at work here, too, is the opposite: traditional medicine being evoked to legitimate charismatic power.

In June 2007, Jammeh was also awarded the honorary presidency of WANTRAP, the West African Network of Traditional Practitioners. As the national newspaper *The Daily Observer* reported:

> The Secretary of State for Health Dr Tamsir Mbowe and the entire medical profession, including the President's medical team, take this opportunity to extend their joyous congratulations to His Excellency, Alhaji Dr Yahya Jammeh for this distinguished honour from the West African Traditional Practitioners. This honour is a further proof of the effectiveness of His Excellency's traditional herbal cure for HIV/Aids and the cure of hypertension.[55]

Although it is unclear why this award in June was not reported until September, it is the case that many people who saw the story in the newspaper or heard it on the radio were convinced by the official nature of such a body, and this further reinforced the president's position and legitimacy as a traditional healer – and indeed the legitimacy and authority of traditional healing - within a West African context. Moreover such legitimisation extended beyond this context to globally-recognised 'complementary' medicine when in February 2008 the president was also awarded an honorary degree in Herbal and Homeopathic Medicine from the Brussels-based Jean Monnet University. As a newspaper article commented:

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[54] http://www.statehouse.gm/images/hiv-aids-batch4/index.htm
[55] 'President Jammeh appointed Honorary President of WANTRAP', *Daily Observer*, 21 September 2007

In accepting his degree the president thanked the Professor and the university who so honoured him. "May God reward you for what you have done because it is better than thank you. It is a big surprise that it came from those quarters who initially would hang me in the street as a lunatic and an irresponsible somebody, and somebody who is out to endanger human life… It would be very irresponsible of me as a president, typically an African, to play with a disease that kills more blacks than any other race by falsely claiming I can cure HIV/AIDS when I cannot. I will rather die than do something that mean".[56]

In some commentary, the president's treatment regime has, in these respects, been constructed as a valuable contribution to plural perspectives on therapy and science in the global response to AIDS. As a Gambian student in the UK put it:

This is perhaps a turning point in the struggle against one of the deadliest viral diseases that has defied medical science for over a quarter century. It has indeed brought to the forefront, the role or potential role of spiritual and herbal therapy in the fight against a dreadful disease…. Modern medical science has monopolised disease diagnosis and treatment - a no go area for herbal and spiritual therapy, even though it has proved effective in the past. The failure of medical science to find a cure or even a vaccine for HIV/AIDS in more than a quarter of a century has seriously undermined confidence and perhaps reinforced the need for a rethink in strategy in dealing with the AIDS pandemic.[57]

There are many ways in which the Gambian president easily lifted the mantle of traditional healer – as familiar to him as to his fellow Gambians. He is a Jola, from the Foni, as discussed earlier an area renowned for healing and healers. His home village of Kanilai, much enriched through his rise to power, also became a site of his healing programme, with promises to build a treatment centre there for his many different patients.

President Jammeh's claim to hereditary powers builds well into local understandings. The mixture of herbal and Islamic medicine used in his treatment programme also follows naturally from the usual practices of healers around the country, as does the use of local herbs. The recipe, or recipes used were closely guarded secrets, also echoing traditional practices and the culture of secrecy around powerful healing

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[56] 'Honorary Degree for President Jammeh' *Daily Observer*, 21 February 2008
[57] 'Beyond the confines of medical science: The president's AIDS cure debate', Kebba Dibba, http://www.statehouse.gm/article-hiv.htm, Accessed June 2007.

knowledge. To claim to hold such secret knowledge also boosts the importance and legitimacy of the practitioner.

However, there are many other ways in which president Jammeh's particular brand of traditionalism is a bad fit to the practices of healers and the expectations of other Gambians. Throughout 2006, before the 'breakthrough', although there were healers (advertising on radio and in newspapers) who claimed to cure to HIV, these were not given a great deal of credence. On the whole, community focus groups discussing different illnesses consigned HIV, along with other 'complex' or 'new' illnesses, to the clinic rather than for *morfinjaara* [black people's medicine].

The president himself also strays from what might be expected in his practice. Although inherited through a family connection, the claimed genesis of Jammeh's powers is divine – from Allah, rather than the more usual *jinni*, and he was careful to keep his religious symbolism Islamic rather than the more usual mix of tradition and Islam in his HIV 'cure'. Since this time, particularly in treating infertility, the president has gone on to do battle with witches, as well as speak with devils. The use of his 'divine touch' in herbal massage (although with the precaution of plastic gloves to protect him from his patients) is also foreign to the practice of healing as explained by practitioners and patients alike; the closest similar practice being the use of the 'divine touch' of the Koran in washes in which the text is dissolved.

The sense of connectedness, so vital in traditional healing, is also missing in president Jammeh's programme. First, it lacks the usually-expected payments and reciprocity. Second, people find it unlikely (although unknowable) that the president spent time in the forest correctly greeting trees and collecting his herbs. There were many rumours which circulated both the support groups and society in general that he had a healer from Senegal (Casamance) in his employ, and that it was this man, in fact, who could perform the ceremonies and make the concoctions used. It was rumoured at one time that this man had 'escaped' and was pursued across the border by the security forces.

The president's use of diplomas and plaudits, from the very 'western world' he derides, to back up his claims, speak to a legitimising process which was not fully secured by traditional means, so required the pulling-in of every possible tool to

attempt to shore itself up (Fassin and Fassin 1986). Furthermore President Jammeh is unable to divine what is wrong with his patients and does not diagnose – demanding instead that they bring 'proof' of their HIV status in the form of a letter from their physician. The following section elaborates further on instances such as this where linkages and cross-contaminations from bio-medicine became important parts of the president's cure and its justification.

4.4.2. Being cured – not treated; numbers as evidence

Despite the apparent opposition between the framing of the president's treatment programme and mainstream, biomedical AIDS discourses, president Jammeh and his supporters have in practice mimicked and co-opted key strands of these. There is a strong current of biomedical scientific language in the explanation and justifications made for the 'cure' given by the president and his supporters. The medical qualifications of the then Secretary of State for Health, Dr. Mbowe, as well as other supporters of the president have been stressed, and the president and his nephew who assists with the treatment are referred to as doctors in public speeches, all repeated by the state-controlled media[58].

Thus as well as justifying his cure through Islam, traditional medicine and personal-political power, president Jammeh has simultaneously sought validation from the western-biomedical system that he rejects. In particular, the co-optation of both numerical and testimonial 'evidence', which I discuss in chapter seven, of treatment efficacy from biomedical discourses and mainstream Global AIDS programming have been central to the president's ability to attract and maintain support for his claims, including from people living with HIV. This is also related to ideas about the importance of display and appearance, which are described in detail in the following chapter.

Shortly after beginning his treatment programme President Jammeh sought 'scientific' evidence of its effectiveness by commissioning laboratory tests of blood samples of treated patients in Senegal.

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[58] http://observer.gm/africa/gambia/article/2007/11/26/dr-mbowe-bags-new-job; http://www.statehouse.gm/4batch-hiv-dischrg_270408.htm; http://www.statehouse.gm/images/hiv-aids-batch4/index.htm

> This is a scientific proof that President Jammeh's claim is true and have been verified to be true through the most rigorous scientific test namely a lab in a medical school[59]

That blood samples were sent abroad – rather than run at the more than adequate national laboratory in the Royal Victoria Hospital in Banjul – can be seen as an appeal both to rational-scientific concepts of objectively verifiable data, and to external authority and legitimacy – the authority of international science. By producing results outside the Gambia criticism that positive results were faked, which might have emerged had the tests been conducted at home, was not possible. The results of the Senegalese tests were published in the national newspaper, *The Daily Observer*, under the headline 'Proof of Cure'. When the Senegalese laboratory claimed that this was a misinterpretation of the results, *The Daily Observer* ran an article in response interpreting this refutation in geo-political terms. The article invoked longstanding regional political-economic tension, and stated that the Senegalese had always been jealous of The Gambia and were now envious of its AIDS 'cure'[60].

The CD4 counts and viral loads of the president's patients were shown, and remained available on the president's own website until at least August 2010. Each individual's name and picture is shown with the original letters from the Senegalese laboratory, with results available by clicking on their faces[61]. Further letters and results are also available from the Moroccan tests[62]. While such public portrayals raise obvious issues about confidentiality and disclosure, all discounted by the president, it also illustrates a seeming openness around 'results' and a respect for scientific findings which 'prove' his case. This is despite the fact that these results – for those able to interpret them according to their usual biomedical meaning – quite clearly show a group of people who are all HIV positive.

CD4 counts and viral load tests are, more conventionally, central in the routine biomedical management of HIV. Indeed in a Gambian ART clinic, a doctor described

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[59] *Daily Observer*, 15 February 2007.
[60] http://allafrica.com/stories/200702230783.html
[61] http://www.statehouse.gm/hiv-results/index.htm
[62] http://www.statehouse.gm/hiv-test-rsult2_150307/index.htm

what he called 'treatment by numbers': with complex tests, diagnosis and treatment become in effect a numbers game, involving taking measurements and prescribing drugs to keep within, below or above certain numbers. For people who attend clinic regularly, and particularly those who have started ART, the CD4 counts and viral loads are familiar measures, as described above. Yet for people living with HIV, the numbers – and a statement such as 'my CD4 is 600' - are not as fixed a certainty as doctors and scientists would like to imagine, and a new version of what they mean could therefore be appealing. 'Treatment literacy' is a gradual and varied process. Only a few of those taking ARVs can speak fluently about what drugs they take together for what reasons; many more have only a functional grasp of the numbers, having heard about them in clinics and workshops, and are open to diverse interpretations of what they might mean to them.

To legitimate his treatment claims, president Jammeh has thus looked to biomedicine and its numbers, yet he has cleaved these from the context in which they make biomedical sense and given them new meanings. From a biomedical perspective, high CD4 and low or undetectable viral loads of treated patients displayed on the statehouse website do not constitute a 'proof of cure'. For people who are HIV-2-positive this would be expected. For those who are HIV-1 the results also tally with their diagnosis[63]. Furthermore a good diet was, for many of these people, impossible before they entered the president's programme, and the health benefits of the food and other material patronage associated with being part of Jammeh's treatment regime could improve people's health. Nevertheless, for people living with HIV, it was difficult – looking at these numbers - to rule out the efficacy of the president's treatment. With their experience of tests and their own numbers in their heads, some people living with HIV moved very quickly to discuss the positive value of traditional medicine in general, while others reflected that maybe this treatment was 'the same as ARVs'[64].

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[63] HIV Physician in the Gambia, pers. comm.
[64] Support group members in informal discussion

As time moved on, however, uncertainties and ambiguities in the president's position became more apparent. As a group of 'cured' patients was released on October 24th 2007, *The Daily Observer*'s editorial the following day was less sure:

> It was therefore apparent that when the first CD4 counts results were announced proving the success of President Jammeh's treatment, that indeed we have picked up a huge fight globally on behalf of The Gambia and humanity. He said that those whose viral loads are not detectable, it does not mean that they are discharged from the treatment. President Jammeh did not say that he cures AIDS, all what he said was that he treats AIDS and gets rid of the virus from the patients' bodies. He said that it is the viral load that makes one an HIV/AIDS patients and the traditional medicine that is given to them fights the viral load in the patients body. He further stated that the HIV virus have been eliminated in some of the patients and that some of them are free from the virus. He further stated that we now know how long it will take to completely eliminate the virus in the bodies of the patients. He said all medicines have side-effects, but his traditional medicines have no side-effects, noting that all its side-effects are positive.[65]

Indeed the president's speeches and statements, as well media and website reportage, exhibit many similar instances of confusion and contradiction. Although the example above was a first instance of equivocation over whether the treatment constitutes a cure, the statement is still replete with ambiguities. Mixing of the figures and meanings from viral loads and CD4-counts, in the absence of a clear statement as to what they 'should' mean, has been a common thread in the president's position from the beginning of the controversy. The numbers have been drawn into Jammeh's programme to confer a legitimacy which seems to be independent of any clear re-interpretation, relying rather on the fact that the majority of people are not clear as to what they do mean.

4.4.3. The body multiple

People living with HIV, as this discussion of the presidential 'cure' exemplifies, are the focus of intense attention; their body, symptoms and actions and relationships. People living with HIV, their virus, immune system and person are inscribed with meanings, judgements and proscriptions which reach from the medical into the personal. As the following chapters elaborate, the spaces which are available to these people or which they can try to shape themselves are limited. Even these most

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[65] http://allafrica.com/stories/200710250922.html

personal of spaces, the physical body, is described and acted upon by diverse systems: belief systems, as described above around health and healing, as well as of domesticity and society, as the following chapters describe further.

Returning to the three spheres of the body-self, -social, and -politic (Schepher-Hughes and Lock 1987) the wider social and political spheres which relate to this analysis are followed on in the next two chapters which pick up these dimensions. The following chapter, focuses on the 'domestic' space, and the social experience of illness within the home and community. Chapter six, treatment spaces, looks at the clinical space where illness is diagnosed and described, a political space in which the body is regulated through systems of surveillance and control.

This chapter shows through the frames available to people living with HIV a process of de-pluralisation with the introduction of strong biomedical discourses, as discussed in the previous chapter. This was followed by a re-pluralisation, with the president's 'cure' programme. However, these are not complete shifts; incomplete processes which are meshed together in unexpected ways. The story of this chapter reveals a co-existence of multiplicity of understandings about and around their bodies, which people must negotiate between depending on their social and political circumstances and contingencies – which links again to the subsequent chapters which explore such spaces.

5. Domestic Spaces

While the previous chapter considered the body-self, this chapter expands this focus into the body-social (Scheper-Hughes and Lock 1987). It sketches out the settings in which people live – the circumstances and social situations that shape daily life in peri-urban Gambia. It is beyond the scope of this chapter to include all aspects of life, so here I select some aspects which are most relevant to the ways in which people make choices around illness for themselves and their families. This chapter takes a broad look at issues around health, illness and treatment seeking in the Gambia, and places HIV within these understandings. It also tells the story of being HIV+ in the home – within the family and community – and the dilemmas and conflicts, as well as the support and help that this brings.

The general public's engagement with HIV in the Gambia is limited, although the advent of the president's 'breakthrough' in early 2007 brought it much more to the fore. Before this point, during my fieldwork in 2006, there were few mentions in the media of HIV work and although there were many billboards and posters, and IEC (Information, Education, Communication) campaigns on television and radio running through NAS and the NACP (with HARRP and GF Funding), most people continued to believe that HIV was not a problem in the Gambia, although most had heard of it. The Behavioural Sentinel Survey on HIV/AIDS for the Gambia (2003) found that 95.6% of those interviewed had heard of HIV, and around half could give a good description of methods of transmission and prevention. However, this survey also asked people whether they would keep a relative's status secret if it was revealed to them and, with wide variance for region and gender, many said they would not. In this tightly knit and strongly related community these links, and any stigma within them colour an individual's life and also their vulnerability. One conclusion of the report stated;

> What seems to come out of the data is that females are more likely to stigmatize than males. More than six females in ten will not eat with an infected person; over four out of ten females will not care for an HIV/AIDS; over half of all females will not keep the HIV status of a family member and nearly half of them said a student with HIV should not attend school. Considering that females are the main caregivers in Gambian society this pattern strongly indicating discrimination is of great concern particularly in

light of possible home based care for HIV/AIDS victims. In addition this attitude to people living with HIV/AIDS will not encourage them to be more visible and vocal in the fight against the disease.

<div align="right">Jallow 2003; 40</div>

It is clear that community views colour both the stigma experienced by people, evidenced in narratives of exclusion and difficulties in the home and community, and also 'self-stigma' – the fear of such negative reactions from others should you choose to disclose (Alubo et al. 2002; Awusabo-Asare 1995). As outlined in the previous chapter, the bodily experience of HIV spreads into the domain of family relations, the body-social (Schepher-Hughes and Lock 1987), as people fear the recognition of their illness in others through the symptoms they display, and negative reactions based on this.

The sections which follow look at issues which are particularly pertinent to people living with HIV. I begin with an overview of factors that shape social organisation at a community and household level in the Gambia. This includes a discussion of ethnicity, religion and of links of patronage and control, the structures which hold Gambian society together, as well as the micro-politics of polygamous marriages and compound life, and gendered decision making in domestic spaces.

The second section situates people living with HIV within this sphere, with a discussion of disclosure, and so also of stigma. I discuss how these pressures and the experience of daily life in the Gambia shape the way in which people feel they are able to disclose, to whom and for what purpose, and the stresses that relationships and networks exist under. I go on to discuss related issues around fertility, pregnancy and childbearing and the importance of these issues both within this context and for people living with HIV in particular. Finally, I discuss gender norms in the Gambia and how they can affect health and treatment seeking behaviour, as well as influence the ways in which 'sick roles' are played out – for instance within shared family or individual rented spaces.

5.1. *Domestic Spaces – the politics of everyday life*

5.1.1. Ethnicity and ethnic stereotypes

As outlined in chapter 2 (see section 2.2.3) there are many ethnic groups in the Gambia, with some fluidity between these identities. Historically, waves of migration and intermarriage have occurred (Wright 2004; 74). Similarly, it is often the case that a 'Mandinka' who has inherited this ethnicity patrilineally, as is the norm, will have been raised in a Jola maternal home, and so on. Thus most people are multi-lingual and while they may identify themselves within one group, they are closely related to another.

This is particularly the case taking into account political associations. As outlined in chapter two, Wolof became a dominant group during colonial times; Mandinka leadership – as first people – gives this majority group a dominant identity. More recently the president has bestowed his patronage of his own ethnic group - Jola. It is common practice to send children to be raised in other families, whether to strengthen their parents' ties with a politically prominent family; to urban areas for school access, or, for girls, to help in households where female labour is needed[66]. The ascendancy of Jola regions in recent years through the patronage of the president has shifted the balance of power which can be perceived between different groups. On the whole the Gambia does not have serious ethnic tensions – certainly by comparison with some countries in the region. However, historical and political inequalities – be they real or felt – set up oppositions between groups, and stereotypes of 'immoral' Jolas and the raucous behaviour at their ceremonies, or 'proud' Mandinkas, are common.

Such stereotypes impact may upon people's experience of being HIV+. One man recounted to me the story of how he became infected with HIV; he had a relationship with a girl, who, it turned out, had other boyfriends. He believed this was how he had become infected. As he finished telling his story another woman sitting nearby, in the support group centre, said "she was a Jola?" He said yes, she was. They nodded, it seemed this was to be expected. A common conception is that Jola, and particularly

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[66] Household and gender roles are further described below.

Jola women, have many partners – and that their initiation ceremonies involve multiple sexual encounters – and as such are a 'risk' in this way. I did not witness any discrimination based on these views within the support groups, and there were, of course, Jola members.

Joking relationships

Despite the blurring within and between these ethnic categories, which are arguably historically the externally imposed definitions of outsiders (Charry 2000; 18), and although such ambiguities are admitted, for Gambians these are set identities. When people meet, elaborate extended greetings and questions establish the surname and thus the ethnicity and clan identity of new acquaintances. This places people in a web of understood relationships between each other and the society as a whole.

Between people of different ethnicities, and within these of different surnames and clans, there are 'joking' relations. These have been described to me as relationships which if they resulted in violence – between the specific partners of the joking relationship – would result in serious repercussions; a disordering of the world. Unlike other studies of these relationships, which "Ethnographers had reported from North America, Oceania, and Africa instances of a custom by which persons standing in certain relationships resulting either from kinship, or more usually from marriage, were permitted or required to behave towards one another in a disrespectful or insulting way at which no offence might be taken" (Radcliffe Brown 1949; 133), in this context they are society wide, rather than just within the family, but this reinforces the sense that Gambians have, and which they often say, that across the country 'we are all family'. Such relationships perform the same peace-keeping function, as elsewhere (Radcliffe-Brown 1940). Thus joking holds the social order firmly together, and people recognise and play their parts daily. These relationships have stories and myths going back to the history (or depicted history) of the relations between these groups or families through times of conflict, as well as reiterating the family occupation for example for blacksmiths, leatherworkers, *jails* [praise-singers] and other musicians. Therefore not only relations but functions and status are also set and repeated through these mechanisms.

Bellagamba (2009) discusses the ways in which silence functions in Gambian society, as a positive attribute and one which takes self-control and 'patience' to reinforce existing hierarchies; to talk about worlds can destroy them. Thus other than the 'official' versions of family history sung at ceremonies these hierarchies are not repeated, and certainly are not challenged. In her discussion of slavery Bellagamba describes a reticence to speak among the descendants of slaves, the dominant ideology being of the positive values of silence. To speak is to diverge from this norm and therefore behave in a way socially devalued by the elite it protects. Although not spoken of in these terms, this valuing of silence and secrecy may explain, alongside individual and psychological reasons, the reluctance of people living with HIV to disclosure their status. This opens interesting questions about the transfer of ideologies around the benefits of disclosure to different contexts, as I discussed in chapter three.

These ties are reinforcing – everyone knows their place in the world, and is connected. For people living with HIV such ties continue. Such ties are also important within clinic environments; where often hierarchies between staff and with the patients within that environment intersect with these alternate links and hierarchies, altering dynamics which would seem set by institutional positions.

5.1.2. Islam

Religion is a prominent and determining aspect of social and political relations across the whole of the region, with Islam the major religion in West Africa, at around 95% of the population, as described in chapter 2 (see section 2.2.3).

As such religious leaders play an important role in the community. Islamic institutions and ceremonies dominate social and community life. Many families will send one child to Islamic school, and the rest to 'western' education. Islamic codes of conduct for men and, particularly, women dominate the cultural landscape. Larger or better off families may have a small mosque within the compound, and the building of a mosque, or contributing either financially or in labour to its construction, stores up grace in heaven.

Islamic festivals are the most important events of the year; *Koriteh* [Ed-Ul-Fitre celebrating the end of Ramadan] and *Tobaski* [Ed-Ul-Kabir, the time of the pilgrimage to Mecca, recalling Abraham's sacrifice of his son] are the two major festivals. The month of fasting for Ramadan is part of the structure of the year, bringing the same hunger to all, rich or poor. The performance of piety is important on a daily basis; with prayers and mosque attendance – for men, women should pray at home – a marker of respectability. Community members as well as the Imam will also preach from the mosque, which, in some urban areas, has a loudspeaker system so that some community members reaffirm a strong Islamic stance on issues such as the control of youth and women, bad behaviour and the importance of traditional and Islamic propriety being upheld. These strong moral messages feed into negative stereotypes of HIV, and those who contract the virus; those who transgress, who 'play around'.

Dress, gender, morality

One way in which piety is performed is through dress. Western clothes are common, particularly for men. Day-to-day most people wear Gambian traditional clothes, and always on a Friday, for prayers. For women especially wearing western clothes can break norms over skirt length and wearing trousers, while for men there are no such sanctions. One NGO which ran health education programmes in schools has an annual national drama competition for the schools where they work. HIV is one of the main strands of this work, encouraging students to stay in school and avoid early sex, discussing coerced sex, for example, and other issues that young people face. The dramas which reached the final (June 2006) all focused on young girls[67] finding they were HIV+ - with much wailing when the diagnosis was given. All of the girls who tested positive wore western clothes as a signifier of their 'loose morals' or foolishness. Most had a sensible friend – in full Gambian dress and head scarf – to counsel restraint and offer sympathy. I interpret this as part of underlying societal judgements on western behaviour and morality. The youth trainers who go into schools are young Gambians and the culture of the organisation at this level does not seem to be influenced by this organisation's roots in Canada. The social controls on women and girls are very strong; many people say that they should never leave their

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[67] None of the drama groups depicted a man/boy receiving his HIV test result.

father or husband's compound unescorted. Thus girls who are seen to transgress – in sexual conduct especially – are strongly sanctioned. This is despite the fact that for many young girls coerced sex with older men, including teachers, is a well recognised problem.

For festivals it is customary to have a new set of clothes, in Gambian style, as are worn at prayers on Friday. For young people, and most women, to have new clothes for *Tobaski* and *Koriteh* is a necessity not a luxury. For some young people there is also now a second day, the day after the festival, when new western clothes are worn, in seeming opposition to the Islamic meanings of the festival. People struggle to find money for these expenses, even in times of economic hardship, and it can create tensions within the household as husbands struggle to fulfil the demands for money from all wives and family members, with clothing and appearance being as important as the festival food and drink or prayers. Such expectations, as will be discussed in later chapters, are difficult for all. People living with HIV, men especially, feel that they are letting down their family members if they cannot provide. This raises tensions around volunteering within the groups and the lack of salary for people who go out everyday to 'work'.

I was told by a few informants – health workers – that to be a tailor is a risk factor for HIV. While it is impossible to verify this, the explanation they gave was that for Gambian women to have new clothes for occasions such as Ramadan is so important that if they cannot afford to pay they may engage in sex in exchange for their clothes. It is interesting that the need for new clothes – the importance of appearance – should be conceived as so strong.

Ramadan

The distinction between appearance and reality, and public pressure, is well demonstrated through the month of Ramadan. People in the Gambia fast from dawn to dusk, and nothing must pass the lips; no liquid, and many people spit to prevent themselves from swallowing even saliva. Smoking is also prohibited for this reason, for men - only loose women smoke. Many people told me that chewing on the twigs used to clean the teeth, to allay hunger, is also 'cheating'. However, many people do 'cheat', sipping water in their houses. For people living with HIV, and especially

those taking ARVs, this presents a problem. Many support group members said it was their duty to fast as much as any other person, despite the difficulty. The timing of drugs could also be shifted, from twelve hours apart (nine a.m. and p.m. for example) to coincide with the starting and breaking of fast. There were equally others for whom this necessity was removed because of their status; one support group member told me "No, I do not fast. God wants us to be well" (HIV+ Male, in conversation, September 2007). Those who are ill, as well as women during their menses and pregnant women, are excused from fasting. However, since to eat or drink in public incurs public censure, or questioning, many people who are HIV+ feel pressure to keep fast, at least in public. This avoids awkward questions in the home.

From family structure and initiation ceremonies and practices, traditional religions and healing, as described in the previous chapter, there is a cross-over between the centuries of Islamic influence and various other influences and trends blending together. Thus it is difficult to separate one system of beliefs from another or to see them as contradictory, but perhaps more useful to see them working together for people who may be more or less devout Muslims, but may also take on aspects of other belief systems in particular circumstances. Here there are links to systems of knowledge and beliefs, and practices related to these – about the body, healing, purity and impurity – which are played out in these spheres.

5.1.3. Community and Family

As outlined in chapter two the decision was made early on in my fieldwork to focus on Mandinka, linguistically, and also to be resident in a Mandinka compound. However, while there is some bias in my experience towards this ethnicity, in peri-urban Gambia, this is not significant. Most communities, from the large urban areas to smaller villages, have more in common than in difference despite differences in ethnicity. Outside the coastal peri-urban areas, towards the southern border with Senegal, for example, in a predominantly Jola area, the organisation of communities and families, as well as festivals and events would be somewhat different. However, just as Linares (1992) explains the predominance of Mandinka culture in Jola areas of Senegal, similarly a focus in the Gambia on Mandinka is particularly illuminating of practices which are now widespread, particularly in the study area of this research: Banjul-Kombo-Western Division.

Kinship/territory/family structures

As chapter two describes (2.2.3), the structure of communities is centred on families –
the 'founding families', and the power relations which play out within and between
these powerful and rooted landowning families and the various 'strangers' within the
region (Murphy and Bledsoe 1989; Beckerleg 1993; Ferme 2001).

The *Alkalo* [chief] of any town or village will usually be from the founding family,
and there is great pride for members of this family – again recognisable from
surnames and the greetings which place people within this structure. Political
difficulties have occurred in many areas where there are now two *Alkali*. In a growing
number of communities the traditional leader has been replaced by the government
with a second *Alkalo*. However, these changes are often not accepted by the
community. I have visited several villages and areas where the loyalties of community
members are split between these two figures, one holding local-kinship and the other
national-political sanctioned power, which creates problems for outsiders wishing to
follow the correct protocol in paying respects to the *Alkalo*. During the 2007 general
elections a similar problem occurred when the APRC removed their backing from a
number of their candidates. However, these men (all, were, of course, men) were
prominent in their communities, the natural candidate, and so some stood as
independent candidates against those put forward by the party. This was
predominantly in the South-west of the country, around the President's home area.
Thus the APRC and the president created a situation in which people were voting
across split loyalties; those to the president and APRC, and those to the local 'big
man' and usually uncontested candidate. This area would not have had elections at all
– seats would have passed uncontested – had the president not removed his support
from these candidates. In some areas the old candidates, now independents, ran. A
few of these won, causing a scandal. These people were afterwards allowed back into
the party. This illustrates the ways in which traditional and political party-based
structures are intertwined, as are the ways in which they build legitimacy and loyalty
from the community, as, in fact, has been the case since colonial interventions in
traditional leadership (Bellagamba 2004, see Kea 2004 for a description of how these
tensions played out specifically in Brikama, one of the sites of this research).

The current political situation in the Gambia is one of fear and distrust, where neighbours know who in their street the NIA[68] informant is, and are careful when and to whom they speak. Political and press freedom are very limited and people live according to ties of loyalty and affiliation. Any dissent could result in arrest or disappearance, and political opposition is stunted, under President Jammeh's "authoritarian rule" (Saine 2008). Forced labour is also a feature of community life. These can be *kafoo[69]s* pressed into service of their community, cleaning or building. The language used to describe this community service draws comparisons between the forced labour experienced under colonial rule and that of the current government (Bellagamba 2002).

Strangers

Due to the structure of hierarchical and patron-client relationships, strangers play important roles in the community. Many people travel outside their home area to stay in another compound, often that of a family member, becoming a client of that household and its head. Other compounds had several strangers from neighbouring countries as well as from different parts of the Gambia. It is usual for family compounds to have what are referred to as 'boys' houses' where strangers can stay. Traditionally these strangers provided their labour to the household; however, in the increasingly monetarised urban areas in the Gambia, these are becoming more commercial rental arrangements. That is not to say that the links of duty and responsibility are not also recognised from the customary system, even where payments are made. These host-stranger relationships are part of a web of patron-client arrangements, which are seen across West Africa (Brooks 1993; Linares 1992; Beckerleg 1993).

Mobility is the norm for many Gambians, from adults working abroad, at the coast or as strangers in another area, to children. Families that I knew both sent and received children. This could be for many reasons, for the benefit of either family or the child – being closer to school or learning a skill for example. This practice also raises the interdependence of families who are raising and supporting each other's children.

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[68] The National Intelligence Agency, much feared and with a network of informants widely known to stretch through the country.
[69] Age-peer groups – described in detail in chapter two (2.2.3) p.47

Mobility is also a factor in HIV transmission – a 'risk factor' (UNAIDS 2001). Many people within the support groups had travelled extensively around the region (particularly the men) or their husbands and family members travelled. Similarly support group members who were from other countries had travelled for commerce, or escaped conflict. It is widely accepted that this is a 'risk factor' in the Gambia, and many people's stories about how they became infected involve travel. One interesting example is the practice of civil servants – for instance, agricultural or health extension workers – being posted away from their families in other areas of the country for long periods. Group members, health and NGO workers all spoke about this as a 'risk' and a necessary target group for education campaigns.

Status and caste

As Beckerleg describes in detail (1993; 49) there is historically a 'caste' system in operation which centres on roles; freeborn, craftspeople, and slaves. These groups each have different roles within the community both in terms of occupation and symbolically, and also in relation to each other. As discussed above, these are recognisable heritages from the family name of an individual, and are part of the persons 'character' and can constrain their options. For example while 'all Kuyates are musicians' one young man, a Bojang, told me that although he was a talented musician and wanted to pursue this, as he was a 'warrior' and it would shame his family, he would not be allowed.

While for many in urban areas the traditional occupations are not available, they do continue to some extent. Also it is often in the villages, to which people are still connected, that these links between families and occupations and status remain. As discussed in the previous chapter, while in the urban melting pot such distinctions may seem to fade, the assumptions and allusions behind them still remain (Conrad and Frank 1995).

For those of 'low' status within this system there is some residual stigma. Bellagamba (2009) describes the ways in which those whose names denote slave origin continue to feel a sense of non-personhood. In this society your wealth is in people, and the duties they owe you (Bledsoe 2002), and slaves did not have control of themselves,

and significantly their children. Moreover a sense of fatalism which pervades society dictates that you should stay where God put you, be this in terms of status or wealth. In Bellagamba's analysis the importance of silence as a mode of social control, in terms of slavery, can also be seen to cross into other areas. As with *Jali* or *griots* and praise-singing, the powerful need not speak, as their worth is spoken for them, for a price. Thus it is possible for those descendants of slaves who have made money to purchase such praise and reinvent themselves, however, often the naming system gives them away, among other signifiers of their origin.[70] While these 'old' ways are blurred in urban areas, and many youth do not fully understand the workings of the systems there are traces of such relationships, for example in joking relationships. Such relationships cross through all spaces; within a clinic a cleaner may, according to this hierarchy, be more senior than a nurse or counsellor.

Patron-clientage

Patron-clinet relationships are thus integral to understanding Gambian social relations. As described in chapter two (2.2.3) "everyone is indebted to others to a greater or lesser extent… every adult is a patron to lesser people, but a client to a more powerful person" (Bledsoe 1980; 55).

These links do not cease in urban areas, or in the offices of NGOs. In fact they become more important. Outside the more commonplace and accepted norms of village relationships and first families and strangers, the urban environment and the struggle to survive cause people to reach for any links which will benefit them, and these new structures and the resources they control can be seen to function within the same patterns. A powerful patron can be a programme manager, or a health worker; within a hospital or clinic one's ability to jump long queues and receive scarce medications are usually based on who you know. In every situation links are important; I myself have avoided paying bribes because the Gambian travelling with me had the appropriate joking relationship with the policeman at a checkpoint to prevent his being able to push for payment. Where this can be problematic is in the

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[70] Bellagamba gives the example of people who are rich and not apparently slaves having reinvented themselves in this way through *griot* affirmations, but when they return to the village their relatives are buried in the slaves' graveyard, which still exist. Also, for example, a reluctance to marry someone from a 'bad' family or origin, and so on. 'The flowers on the dumping ground grow high, but they do not last' – any success achieved by those of 'low' origin is seen to be 'unnatural' and transitory.

divergent understandings of the different parties: those potential 'clients' wishing to build a relationship on traditional means do not count on the constraints of international funding and reporting that surround the priorities of their 'patrons'.

Marriage, polygamy

Traditional social organisation is centred on polygamous patrilineal and patrilocal family groups. It is usual for a man to have up to three wives, dependent upon his ability to pay brideprice to the family and to support his dependants (Bledsoe 1980). (see also section 2.2.3)

Women move to the kabilo of their husband, although many women are married and remain at home until their new house is ready and the brideprice is paid, or even when the first child is born. Again, this is an ideal pattern which is not necessarily upheld in peri-urban Gambia. For those who live outside of the extended family, norms shift or are broken. Over-crowding can mean that it is not possible to have all the wives in a marriage, or all sons and their wives, living in one compound. Similarly bad relationships between wives can necessitate separate compounds for each. For young wives, second and especially third wives their status can be similar to that of a 'maid' to the first wife. In extended family compounds all wives are subordinate to the husband's mother and any other senior women (as Bledsoe 2002 also describes). The freedoms of young women and the tasks which younger women are allotted – cooking, cleaning, washing, and so on – are controlled by the senior women in the compound.

For people living with HIV their relative status within the compound can thus be important; for disclosure, and if not disclosed in the difficulties faced in escaping household duties in order to attend clinic or support group. One junior wife who attended an up-country support group with her young son explained that she would not be able to attend any future meetings or trainings as she was only able to leave the compound on that day to bring her son to be circumcised. Many junior household members face similar constrictions on their movements, whereas a senior first wife or a man would not have to give any such explanation.

International marriages are also relatively common. Many people hope to leave the Gambia, and travel abroad to get a better life. The ideas which circulate, especially among youth, as to the riches available in Europe or America are reinforced by the spending habits of tourists. For men to seek to marry a tourist is relatively common, and the coastal tourist areas are a well established sex-tourism destination, predominantly for women (Nyanzi et al 2005). Such an alternate route to financial success, while not respectable, is understood. For women whose husbands are abroad this link to the diaspora and hopes of a better life for themselves and their children, and to travel to be with their husband, will usually never materialise. Most husbands abroad have not told their 'white wife' that they also have a Gambian wife and children. In general women have little to no control over their own sexuality; being married at a young age to someone of your father's choice is a common, although not universal, experience. Some of the women in the support groups were in this position; some said their husbands 'did not believe' in HIV, others that they had been abandoned.

Those families that are 'middle class' and have some financial security usually have at least one family member abroad, sending remittances. Many also buy a car which is used as a taxi – either by a relative or rented to a client/stranger. This also provides regular income and employment for the family. As such the 'stigma' which might be assumed to exist for men and boys marrying European women is lessened by the 'good' which comes from such marriages.

Households, gendered responsibilities

As the discussion above describes each household 'nests' within a structure of "hierarchies within hierarchies" (Murphy and Bledsoe 1989; 126), down to the level of compounds[71], where a man and his wife or wives and their children live. The necessity to have children cannot be overstressed in this context, for both men and women, as the purpose of life and the only socially acceptable course of life[72] (Bledsoe 2002)

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[71] Kunda(lu) – compound(s)

[72] Traditionally infertile women (only women can be infertile), *kanyaling,* play specific roles in the community; at ceremonies they can cross boundaries in jest. Dressing and acting as men they can ridicule and mock the senior men, inverting the power dynamics. In a rural community I met some of

The shared living arrangements of a compound are an insurance against one family member having no income. Those who earn income contribute; many people do not tell even close family members what they earn in order to try to save a little, as the compulsion to share what you have with family is strong, it is impossible to resist requests, which are many. In a shared compound, the compound head will be the owner or senior male. His wives, and sons and their families live in houses arranged around a fenced out space. Some older well established compounds are inherited jointly by two brothers and their whole families stay with them, space allowing. Compounds can also take in strangers, renters, and loosely related members, a woman whose husband works away, but is related to the family, for example. All of these household members contribute as they can; financially, in labour or household tasks. Often older men do not have any discernible occupation, but survive from their position in this way.

Compounds function both as social insurance, and as a form of social stabilisation, and control. Domestic tasks and the ways they are divided reinforce hierarchies. Shared cooking and eating is important as an act of community – as important as greetings – to eat alone is a terrible thing. It also spreads the cost and provides all members access to food. Those people who live alone in rented accommodation, while some neighbours will share in this way, do not have the same level of social insurance, particularly in periods of hardship or sickness.

For people living with HIV to disclose is a risk. Such tight-knit communities of family members provide security, and to be ostracised is both distressing and cuts off access to material support. There is little privacy within the compound, and much discussion of the other members, which again can be difficult for those hiding the secret of their HIV-status. When taking ARVs many people say that they hide the drugs in their houses, and as mealtimes are shared this can often mean that drugs are delayed or forgotten in order to avoid exposure.

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these women who had been employed by a local NGO to use this subversive humour to sing, dance and talk openly about issues around HIV prevention, by parodying male behaviours.

Gambians tell you that wives are financially dependent on their husbands – who should provide 'fish money' for the ingredients for the daily meal. In practice women engage in many money making activities themselves (Carney and Watts 1991; Dey 1981; Schroder 1999). Rice is stored for the whole compound, which should be provided by the man. The financial strain of three wives and many children can be enormous, although the status of the man is raised by his being able to care for this many dependants. While there are many good and responsible husbands, who take these duties seriously, there are also husbands who are not reliable. Such circumstances can create tensions between wives and families, where some are seen to receive more than their fair share, or others not enough. For HIV+ women this dependency means that disclosure is a greater risk than for men. Although I have met both men and women who have been abandoned after disclosure, for men this is less dangerous in terms of security and income. Some men reported that their wives had left them, however they remained in the family home. For women who were abandoned by their husbands this is not the case, and they return to their father's compound or move to rented accommodation, often without their children who remain within their father's family.

5.1.4. Livelihoods

In peri-urban areas women also work; they work in their gardens, growing rice and vegetables, those crops seen to be for women. Rural intra-household norms and negotiations about land access and crops are translated into peri-urban settings – yet also overlaid with greater land availability restrictions and other livelihood opportunities (Carney 1992; Dey 1980; Carney and Watts 1991; Schroeder 1999).This is dependent on having access to land to farm. In the more overcrowded areas even very small plots are cultivated where possible. Many women also engage in petty trading, selling the surplus from their gardens or buying and selling other items: fruit or vegetables; homemade soft drinks, sweets or cooked food; household items or cosmetics and perfume. Such trade can often mean outlaying cash in order to make items or buy them in, and can be difficult for many women. Selling takes place in local markets, and also involves travel to the larger markets in Banjul, Serrekunda and Brikama. These incomes can be precarious. As one woman described:

> I do not always have a good diet because my husband has travelled but he does not send money. It is my mother or my sister that sells ice to support us. But it is not easy for us at home.
>
> Young HIV+ woman, interview in support group August 2006

Men's occupations are more varied, and they are expected to make cash income for the household. Groundnut farming has been the main cash crop in the Gambia, but government mismanagement and non- or delayed payments from the centralised buying scheme has made this less profitable. Men who identify themselves as 'businessmen' engage in buying and selling a wide range of products; from second-hand clothes to electrical goods. Many of these items are sent in containers by family members or contacts abroad. Another common occupation is taxi driving. As a car is an item most cannot afford this is often done by arrangement, and again with assistance from overseas. Cars sent back and registered as taxis are often driven by a family member, or rented out for a set fee to another driver. Regular waged income is rare, with perhaps one member of a compound employed. The tourist industry, NGOs and international organisations, MRC and government are all large employers. Other trades such as carpenters, mechanics, tailors and so on provide regular income, and can apprentice younger family members.

Seasonality is an important factor in the Gambia. This is in terms of the regular growing season and the shortages that are felt during the rainy season. There is also the tourist season. During this time many young men from upcountry travel to coastal areas to gain work, or 'hustle' tourists – often seeking to find a sponsor, wife or route abroad as well as short term gains. In the rainy season many of these young men return to the village to work on family farms, and re-integrated into traditional family structures are insulated against a lack of income. This is a factor in urban overcrowding, and increased rents; the 'greed' of landlords.

5.1.5. Single women

Women who have been widowed or divorced can fall outside of these structures. A widow would traditionally be inherited by another male within the household; usually the husband's brother. This practice functions to keep both the women and her children within the extended family, and therefore protected, fed and cared for. Children are inherited by the father, as they inherit this name and ethnicity. For

women who are divorced this often involves being sent away both from the extended family in which they have lived since marriage, and from their children. Although divorce is spoken of as being rare, and against social norms, observation of community life shows that it is very frequent. Many people are married several times, whether this is through the death of a partner or divorce. Divorce is also quite simple – particularly for men, sending a wife away is all that is required. It is also not unheard of, despite the increased vulnerability it brings, and the social stigma attached to unmarried women, for wives to leave their husbands. The interviews and informal contacts throughout my fieldwork show that for many people their situations are not fixed, and can change dramatically and suddenly;

> We are renting, we used to stay in a big compound but when my father died my mother married to another husband. But she has divorced with him, so now we are renting with my mother. My mother sells at the market for our daily living.
>> HIV+ woman, not support group member, interview in clinic August 2006

> Life with me was cordial with my family, I was in my family compound. But now I am renting because my children were always fighting with my brother's children.
>> HIV+ man, not support group member, interview in clinic August 2006

Carney and Watts (1990) describe the working of *Kafoos*, age-peer groups in the Gambia. These groups often work or farm together. Traditionally these were the 'age-sets' which went to be circumcised together, as described in chapter two, forming lasting bonds which reinforce the hierarchies of society. In rural areas or villages *kafoos* continue to function in this way. They are also financial support organisations, where fees are paid weekly by each member, and the total given out to one member by a lottery system. This form of group savings enables women to make larger purchases or ease the pressure at festivals or family events. In urban areas women's *kafoos* are purely financial organisations; some women join many different groups, attending several meetings a week. While this means they have to 'hustle' to make the money to pay the dues for each meeting on time, it also increases their chances of taking home a large sum more often, to be used or invested as they choose.

These interlocking systems and patterns of belief and behaviour make up the structures of people's everyday lives in the Gambia. It is however important to remember the role of agency, as people negotiate within these frames to gain benefits for themselves and their families. Bledsoe (2002) sets out 'wealth in people' as a way of understanding the ways in which people act within these structures to maximise the benefits and amass wealth. She outlines the ways in which apparently set systems of control can be manipulated, primarily by those who are the main beneficiaries; older men, but also by others who may appear to be reined in by the system. Women also act as 'hosts' in patron-client relations and negotiations over access to land and resources. Those women in positions of power are linked into lineages and families of founding families, and act to maintain and reinforce the differences that benefit them (Kea 2004).

Different units within these structures hold and deploy different kinds of resources, economic, symbolic as well as support and care. Where patrons of different kinds will be called on to provide aid and protection in difficulty, so they will be expected to reciprocate (Bledsoe 2002). The peri-urban context of this research means that while many of these norms and expectations are strongly fixed in people's minds – concepts of propriety and morality – in practice, in situations of extreme poverty and hardship, many of these norms shift and fade.

5.2. *Being HIV+*

Through the first section I have outlined the major factors which shape people's daily experiences in the Gambia, linking these issues to the experience of being HIV+. Here, I focus more specifically on the social experience of being HIV+, as described by people living with this condition. Firstly I focus on issues around family and community; around disclosure and the fear of stigmatising responses from family members. The second section looks at marriage and the choices people make around sexual relationships and childbearing. The last section looks at the 'sick roles' available to people living with HIV in this context.

5.2.1. Family and Community

> I have never disclosed my status socially because people would point fingers at me.
>> HIV+ woman, not in support group, interview in clinic, September 2006

Disclosure is one of the biggest challenges for people living with HIV. The decision to tell your family, or disclose more widely in the community, is a hard one. Gambian norms around secrecy and silence also work against sharing this information. The risks and benefits are weighed up and on the whole people are afraid to release this information about themselves to others. The power of the negative images around HIV – playing around, immorality, and a fear of *satakurango*, 'the disease that kills' – prevents many people from sharing their diagnosis with even their partners and close family.

> I have never disclosed my status socially because here in the Gambia if you have the infection you are labelled a bad person or a prostitute.
> HIV+ Female, support group member, interviewed in group, October 2006

Women in the support groups reported that it was a common experience to discover that your husband had been going regularly to the clinic only after he had died, when often someone from the clinic would come to suggest the wives came to the clinic, for VCT. As disclosure is a condition of treatment, support group members also tell many stories of people who would rather die than disclose, and access the medicines which would prolong their life. Thus many people do not accept their diagnosis or seek treatment due to fear:

> My life was normal, and I did things in common with my friends, and we'd go for ceremonies here and there, and we dance, chat and play. It did not disturb me in any way, but I was also worried because my husband died at MRC. Then I was seeing almost the same symptoms in myself. My husband used to tell me about HIV, but he never told me he was positive, and he died at MRC.
> HIV+ woman, interview in clinic, October 2006

This can leave people in very difficult circumstances:

> My husband had three of us, and we did our farm work and went to ceremonies together, so it was nice...
> When I did the test I told my brother, as my husband was long since dead, and his other two wives. So I was the only one left with some of the kids.
> HIV+ woman, support group member, interview November 2006

The extent to which people maintain their silence – dying without disclosing to a spouse – emphasises both the fear of HIV and associated stigma people feel. It also implies that within hierarchical relationships such as marriage, and with traditional norms and expectations around masculinity and strength, the value of silence and secrecy in maintaining this overcomes any imperative to disclose and enable the wife and children to seek a test or treatment.

The household dynamics of shared accommodation, be it a family compound or rental compound, add to these pressures. In overcrowded urban areas this can be many people living in close confines. There is a common perception that 'people do point', and a fear of being the subject of gossip. This is not unfounded as people do discuss their friends and relations incessantly, and infringements to 'correct' behaviour are reported to each other; 'Fatou does not pray', or 'Lamin does not greet' signifying public sanction. The appearance of illness can also cause people to avoid even family members out of fear for their own health. While to challenge people directly is unusual, such gossip can be extremely painful. It can also lead to gradual ostracism within the compound, as people are reluctant to cook or share food with people they view as suspect, for whatever reason.

> I do not want others to know, then I will have no friends and I will be alone.
> HIV+ woman, interview in clinic August 2006

Many people living with HIV tell stories about people they have known who have died through 'sitting alone' rather than from HIV infection itself. In this idiom, and perhaps in reality in this interconnected 'family', isolation does kill.

Certainly isolation de-links people from customary avenues of social and material support. There are also many examples of the potential negative effects of disclosure affecting people's actions;

> Ah! You should see me at home, I just sit. I just sit and be quiet. It's not like here [support group] where I laugh and joke. I just sit. If I don't then maybe they will disturb me – saying 'you, with this thing!' So I just keep quiet.
> HIV+woman, support group member, in conversation November 2006

> I did not disclose to my mother that early, until I was told that I should now be starting ARVs. I had fear in me and thought of stigma from other people around me.
>
> HIV+ woman, not support group member, interview in clinic September 2006

> It did make me feel different because I always say being HIV I would not be able to interact with people.
>
> HIV+ man, interview in clinic September 2006

The reality of discrimination after disclosure can make people the subject of gossip. For example:

> It made me feel differently in that I do not do what I was doing before so people also see me differently, as I see myself differently because I have lost all my weight. I have really lost all hope because of the stigma and discrimination around my neighbourhood. The effect it has on my relationships is that my husband does not believe in HIV and my neighbours are always gossiping about me and my sickness and I have lost in my business clients and money.
>
> HIV+ Female, not support group member, interview in clinic September 2006

People also choose those they do disclose to carefully, to ensure their secret is kept safe. Perhaps a spouse is not a trusted friend, but a blood relation would be more so; for women, junior wives in particular, disclosure within the husband's compound where they live could be more difficult than within the father's compound. Because the relationships within a compound may be strained some people prefer not to disclose there, instead disclosing to a trusted friend, and especially within the support groups, as will be discussed in the following chapters.

> I only told my mother and my present husband about my status. I feel that they would keep my status secret.
>
> HIV+ woman, not support group member, August 2006

This choice is often the person who is 'helping' or 'supporting' them. For women this is usually a male family member, such as their father or a brother who is head of the family, and responsible for supporting other family members.

I'm staying with my grandmother and my children… Life was normal and we do things together and go out to ceremonies and funerals and we chat together, as before….

I decided to tell my brother, as he is the one helping me and my mother is old to tell her about my sickness.

HIV+ woman, not support group member, interview in clinic August 2006

Where the extended family are aware, they are not always sympathetic, although some do, after initial shock, come to support their family members;

The experience has been difficult because my husband's family always tell me and my husband they would not eat with us because we are not well. There is a lot of discrimination in the home.

HIV+ woman, not support group member, September 2006

When I got a positive test result I went home and told my mother and our housemaid73. My mother was very surprised and from there did not want to interact with me anymore. In those days I even remember sleeping on the floor, but our maid was very kind and loving and she would do many things for me. My mother deserted me completely…

Right now my mother is with me all the time supporting me and chatting. She has now realised and remembered that I got married at 15 years and that it was an arranged marriage between my parents and my husband's parents. Presently, my husband has divorced me because of my status, and he is presently in the US. I live with my mother.

HIV+ woman, support group member, interview September 2006

The necessity to disclose, particularly to sexual partners and family members, was often discussed in support groups. Many people felt that this was an imposition, and that, especially where husbands had travelled, they should be able to choose a 'treatment supporter' from within the support group. Many people have viewed this necessity as an infringement of their privacy, and that this risked sanction and ostracism within the home. During interviews with people at the clinics and support groups there I found some individuals to give different versions of their family life in these environments. Thus one man from another West African country gave an account of his current family while in the support group, but in the clinic referred

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[73] In this case these were the people living closest together, in the same house within the compound.

back to his ex-wife and children abroad. The clinic are unaware of this new family, otherwise he would be forced to disclose.

One contentious event, towards the end of 2006, revolved around a similar case where the version of the family given to the doctor was not entirely true. A man claiming to have no living wives did in fact live with his wife and children, but had not disclosed. This came to the attention of his physician, who insisted that a fieldworker rectify the situation. When the patient refused, the doctor reacted by sending this member of his staff to the patient's compound to inform the wife of her husband's status. This action was completely outside of all recommendations and rules set down by the relevant committees in the Gambia, and internationally accepted norms of confidentiality. However, when the fieldworker arrived in the family compound, he did not (as instructed) go to the wife and speak to her first. Instead he followed the norms of his society and spoke to the head of the compound – the patient. Thus the threatened forcible disclosure never occurred. The patient did in the end bring his wife and children to the clinic for testing, after much recrimination, and threats of legal action. At one time this man told his doctor that 'we Mandinka do not talk to each other'[74] , implying a more deep-seated reluctance than a fear of rejection.

5.2.2. Marriage and choices

> Things have been difficult because I always feel ashamed of what has happened to me, because my husband travelled for two years and left me and my children alone and was not even communicating with me. Then when he came back and shortly after that he deserted me and my kids. What has really helped me is the support from my brother.
> HIV+ woman, not in support group, interview in clinic, September 2006

Many people, through the death of a partner or divorce, find themselves unmarried after finding out their HIV status. Traditional values around marriage and wife inheritance can place people under pressure. While wife inheritance is a 'traditional practice' which is discussed in terms of transmission, it is a social structure which acts to insure widows against destitution. In many cases the inherited wife is not aware of her status. It is also the case that these family structures can sometimes take care of people without further transmission;

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[74] This story was recounted to me by both sides, the physician reported this quote.

> I was living in my husband's family compound… he was a driver and lived in a big compound with lots of people..
> I was followed up by MRC staff because my husband died at the ward, so they must have known what the reason why… I did not have any problem at that time, I was not sick at all…
> Because I am staying in a big compound I did not tell anyone about my HIV. What I have realised is that my husband's brothers must have suspected the disease that killed my husband. That is why none of them has offered to remarry me. But I still stay in my husband's house with my children.
> <div align="right">HIV+ woman, support group member, interview October 2006</div>

The pressure to marry, or remarry, is also significant. ARVs complicate this situation further as many people do not look sick. Both men and women in the support groups have discussed with me the pressure they feel from family members to marry:

> I do not feel differently about myself [but] my hopes have changed in the sense that my family want me to get married but what I tell them is that I am not well. But they feel that I am joking because I look healthy….
>
> To get married would be difficult. I am not in any sexual relation since when my husband died. I know that I should prevent other [transmission] by using condoms. But I am free [single], I am not having a sexual relationship for five years now. I have only one child, I am not planning to have a child now.
> <div align="right">HIV+ woman on ARVs, not support group member,
interview in clinic, September 2006</div>

For those who are young and unmarried, and especially those without children, an HIV+ diagnosis, and the advice that the clinic gives, causes them to feel very uncertain about the course of their lives. All normal expectations – marriage and children – are called into question:

> It has made particular changes in the sense that people are seeing me differently now because they know that I am sick but don't know what kind of sickness.
> I am not seeing myself differently; I am still the same person.
> My hope for the future is that one day I would be married, because in the rural area a young lady is supposed to have a husband.
> My sickness has not affected my work, only I can say my relationships with the people in our village has changed, when they would gossip and say to me 'we cannot go to the farm together because you are not well'.
> <div align="right">Young HIV+ woman, not in support group, interview in clinic October 2006</div>

For those within marriages, negotiations around sex and children are often difficult, due to these same expectations and norms:

> Since when I learnt of my status my sex with my wife has reduced a lot. What I say to her is that I am more concerned with my treatment than with having sex all the time. We all know where to get condoms when we want to but every time putting on condoms makes me lazy so sometimes it will take me up to two months not having sex.
>
> <div align="right">HIV+ man, support group member, interview August 2006</div>

> I know about prevention but I am not using condoms because I want to have children, but I know about prevention because the doctors told me and my husband to use condoms. But because we want children it is difficult to use condoms.
>
> <div align="right">HIV+ woman, not support group member, interview in clinic, October 2006</div>

> We use condoms since I started using ARVs, my partner knows where to get them. All the time we use condoms…
> No, I have no children yet. But I hope to have at least one child.
>
> <div align="right">HIV+ woman, support group member, interview October 2006</div>

The usual practices of childcare are connected to household organisation. In family compounds junior wives are subordinate to their mothers-in-law, and advice from all about how they should raise their children. The prescriptions around child-feeding to prevent HIV transmission do not fit easily with these relationships; exclusive breastfeeding for six months followed by formula feeding, or only formula feeding. Mothers-in-law and grandmothers, often not knowing the mother's status, cannot see the sense in these strict rules, and will offer young children other drinks or foodstuff, raising the risk of transmission. Equally, mothers – even well aware of the potential consequences – do not feel they can go against cultural norms and cease breastfeeding so early. Those that do manage this have to show great strength, and often have good family support;

> I have one child, the first one died. I am not planning to have children in the future, I am thinking of my health now. I was also told about ARVs and pregnancy, the child I have is not infected because of ARVs and I did not breastfeed her, only milk.
>
> <div align="right">Young HIV+ woman, support group member, interview October 2006</div>

The norms of household responsibility and duties can also prevent people from being able to engage in support groups:

> I was told about the support groups but I did not join because I have nobody to help me at home.
>> HIV+ woman, not in support group, interview in clinic, October 2006

It also true that the support groups are part of this society and share these same norms, as will be described in more detail in chapter six. Even in the groups there are differences, disagreements and 'talk'; "sometimes there is a lot of gossiping, and some of us do not welcome it" (HIV+ woman, Support group member, November 2006).

5.2.3. Sick Role(s)

There are many examples of the ways in which family and compound structures impinge on people's ability to choose their course: be it in treatment, as in the previous chapter, marriage or childcare. These structures also act to support people through difficult times. There are many positive examples of spouses and families rallying to support someone who discloses their HIV+ status:

> I had fear in me but my husband would always tell me 'have faith this is nothing to worry about'. My husband has supported me throughout… When I got a positive test I cried and said I am going to die. But my husband calm me down and said with these ARVs I would not die now.
>> HIV+ woman, discordant couple, support group member,
>> interview October 2006

> What led me to do the test was that one day I had a dream that somebody sat on my chest. Then the next day I started coughing and coughing. Then I started becoming sick, and I started going to marabouts for treatment, but now I can't remember how much. Then I was not improving, but getting worse, and my husband decided we should come to the Gambia for treatment, so that is how we ended up with Hands on Care…
> When I started coming to Hands on Care I was very sick and could not decide for myself which hospital I should attend, it is my husband who brought me.
> I was supported by my husband and the health workers
>> HIV+ woman, not support group member, interview in clinic, August 2006

> My wife and children are supporting me, sometimes if I am sleeping and it is 10p.m.the children would wake me and say 'papa it is time' [to take ARVs]

My husband has his own compound living with his parents and brothers and who also have wives. We do things together, cooking, farm work and so on. Life was normal, and is still like before, only that if people asked for me in our compound [they] would say 'she went to the Kombos on a business trip'…
Now he [my husband] is not alive so I am in my family compound.
HIV+ woman, not support group member,
interview in clinic September 2006

I told my whole family I was going to do the test. I choose my family because they would support me when I am sick.
HIV+ man, not support group member, interview in clinic, September 2006

Throughout 2006, one problem in the Gambia was the denial of HIV. Women who disclosed to their husbands were often confronted by disbelief. This denial led some support group members to take part in public disclosures at sensitisations or workshops;

I want these people to know that HIV is real in the Gambia.
HIV+ woman, support group member, interview October 2006

Such denial can be a product of the spouse's own fear, and often results in divorce or abandonment. However, the events of 2007, and the president's announcement of a 'cure' for HIV countered this major obstacle – no one could deny HIV existed anymore.

Within a compound or household sickness affects everyone, particularly women who are the main carers when a family member becomes ill. Long term sickness and loss of income or labour impacts upon everyone's welfare within the compound. For those who are sick, particularly men who (ideally) bear the responsibility for their family and for cash income, this leads to stress and worry. As described in the previous chapter, people with HIV discuss their symptoms and health within this social context. Most people spoke of their worries around food, income and children.

For those who are known to be sick – whether the illness is known or not – this can lead to difficulties within the compound. For non-productive members of the

household, the discrimination, the gossip and 'finger pointing' outlined above are similar to the 'double stigma' which is experienced by orphans in Zambia (Bond 2005) – sidelined within their homes.

However, many people with HIV do not play a 'sick role' within the household, as they do not disclose. For these people the norms around contributing to the household apply, and they are given no dispensation from such duties based on their status. For support group members, particularly men, there is a need to raise cash incomes. This plays into the role of the support groups and an HIV+ identity as a livelihood strategy, a means of gaining access to income streams; a point which is taken up again in the final chapter. However, such strategies are often not successful as financial gain from taking part in HIV activities – workshops and trainings – is sporadic, and very few people hold salaried positions. This puts pressure on men within the household, particular where they are, apparently, going out to 'work' every day when they visit the support group's centre.

5.3. *Domestic Spaces*

This chapter relates the ways in which HIV is experienced within the home and community. This 'space' can be loosely defined both as a 'Gambian' space; that of norms and structures which govern everyday life and relationships. It is also the family and local community space in which everyone lives. Although this varies from individual to individual the linkages within and between families and communities are built upon these similar structures.

This chapter has outlined those structures which dominate the experience of everyday life. Here I have described, as far as possible, the multiple ways in which ethnicity, religion and family and community structures shape people's lives, their hopes and their possibilities.

Acting within these norms and structures people also express agency and strive to make gains and maintain their health. People living with HIV manage relationships and situations in order to best protect their confidentiality or well-being.

The following chapter builds upon this to bring these structures and understandings into 'treatment spaces'. In each of the spaces which are outlined in the following chapters the 'domestic', as outlined in this chapter, is also present. Within treatment spaces and support societies these values and structures exist. Equally the negotiation of the norms encountered in clinics or support groups by differently positioned individuals also involves the navigation of this Gambian space which exists there also, and so an appreciation of these stresses.

6.   Treatment Spaces

The staff of the three HIV clinics which provide ARV treatment in the Gambia within my study area are busy and committed people. They provide care to some of the most vulnerable patients, and some very sick people. They provide counselling and emotional care as well as tests and treatment. They are part of a national team working in prevention as well as treatment and care, and many of them share their expertise training others. They do all this in a highly pressurised and political environment, with different funders' records and paperwork to fill and different targets set both by external (GF) and internal (NAS, MRC, WEC) governance of their work. Educated and trained to work within this medical world staff view their patients through a very specific lens – that of biomedical disease and treatment – as well as being their neighbours or even relatives.

In this chapter I look at these three clinics from the perspective of the thing which shapes their existence; ARVs. ARV provision shapes the organisation of clinics, their daily tasks and duties. However, the spaces (physical and institutional) that the clinics inhabit, as well as the personnel (their stresses and attitudes) shape the ways in which HIV is talked about and understood. First and foremost in testing and informing people of their diagnosis the clinic staff take a central role in the patient's acceptance or otherwise of this difficult news.

The ongoing – life-long, relationship that the clinics have with ARV patients differs from person to person. One way in which this is most commonly expressed, as in the original design of my research, is through discussion of adherence and 'defaulters'. As set out in the introduction and theoretical framework, adherence to treatment regimen involves many complex factors; as the individual negotiates different institutional and social settings to access treatment, and to gain support. Long's (2000) 'actor-oriented' approach highlights these 'interfaces' with institutions, individuals and situations.

In the structure of this chapter I have carved out two sections from a multiplicity of relations, meanings and practices which are produced at these sites. Firstly a situated

focus, looking at the clinics as places, and the ways the staff function on a daily basis. This includes discussion of the ways in which they are linked, and see themselves to be linked, to other institutions and organisations; predominantly the GF but also as 'porous' spaces within the Gambia, and discussion of the ways in which the clinics are experienced by their clients, reflecting on the relations between carer and client.

The second section looks at how the clinics experienced the changes brought by the president's entrance into the HIV arena; how these changes were experienced by the staff, patients and others within these sets of funding and management structures, and within a biomedical discourse in conflict with the president's 'breakthrough'. Through these changes the interfaces between all of these different actors and positions became charged with the politicisation of their work or condition.

6.1. Treatment spaces – the ARV programme

The clinics are the primary space in which people are HIV+, constituted here as 'patients' rather than people living with the virus. Within the clinics through the enactment of procedures certain discourses are brought into play. These are enforced, negotiated, subverted or ignored, depending on the people and circumstances in which they appear.

Below I discuss some of the main issues around clinic-based HIV treatment. The treatment programme began in September 2004. All three clinics have been through a process of learning and change, as they began, as they settled into routines, as they dealt with the pressures of reporting to GF, as well as increasing numbers of patients and complexity of regimes over time.

Here I focus on some major issues for ARV programmes. Firstly I describe these clinical spaces, in this first section I differentiate and compare the clinics, and their institutional locations. For the following sections I discuss 'the clinic' as a composite of the experiences of these disparate institutions. This acts to simplify an otherwise impossibly broad 'location' for analysis, where the commonalities outweigh the differences and also anonymises the respondents and the institutions to which they are linked. Here I focus on the procedural, the beginning of provision of new treatments, the issue of disclosure, a section on counselling and finally adherence, which was a

focus of my research from the planning stages. In these issues a sense of the de-pluralisation of HIV treatment can be seen – as the biomedical discourse routinised testing, counselling and care, according to the 'correct' ways to provide these services, with negotiation around these structures by both staff and patients. This is not to say that this was a completed process. Within the clinics there was little mention of any alternative, however, alternative treatments were readily available throughout the Gambia, as elsewhere.

6.1.1. The clinics

All three clinics are embedded within larger institutions. Within the RVTH hospital, the HIV clinic is tucked away behind Accident and Emergency, a sharp right by the pharmacy and through more unmarked double doors and you are in a tall room, with sunlight streaming through high windows, people waiting on benches all along the right hand wall.

HoC sits within Brikama health centre; entering through the main gates on clinic days queues of women wait to have their babies seen, a lot of people mill around the between the main clinic buildings and the men's and women's wards. Walking past to the far right of the compound you pass the shared waiting area of concrete seats beneath a corrugate roof before you come to HoC's long low building in the corner, a painted sign proudly giving the clinic name.

The MRC GUM clinic moved during my fieldwork. The original clinic was deep inside the gated compound accessible only through the main gates. After negotiating with the guards over access cards and identification, you pass through the gate clinic, and the waiting area for the bleeding room, then crossing the main quad, diagonally on a well-worn path through the grass. Offices and laboratories looking inwards all around. Next to the ward buildings on the far side of this square, two identical buildings sit side by side, bungalows with small waiting areas in front with concrete seats, and televisions suspended from the roof, locked inside metal cages. On the left the GUM clinic, on the right the TB clinic. In 2007 the MRC compound was cut in half. The old gates on the coastal road, opposite salubrious properties and the British High Commission, now giving access only to the research and residential areas. A new gate at the rear of the compound gave access to the clinics, with more gates

separating the two halves. Entering this gate (as with the old arrangement) there was often a crush of people, guards deciding who can enter. The new GUM is at the back of this area, to find it you pass through all other departments, the large new ward building beside an ancient baobab to the left. People wait in different areas for bleeding, different tests and procedures. Approaching the GUM you turn right, the waiting area is outside on your right, opposite the clinic door, concrete seats under corrugate.

Each of these clinics sits in a different institutional space, with different constraints and issues to contend with, as well as different histories and aims. RVTH is the main hospital in the country; under-resourced and struggling, visiting this hospital can be a long and tortuous route to treatment, unless you know someone who can help you to jump the interminable queues. The HIV clinic in this hospital officially existed, but did not function until the GF money arrived. From then it moved from borrowed space in another clinic to the position described above. The staff in this clinic are given 'top-ups' through GF funding – they are proud of their work and are well paid government employees under this scheme. Other staff within the hospital are aware of these disparities, and they can cause friction; for example the GF top-up goes to the technician who works with GF bought equipment to run CD4 and viral load tests for the clinic, but not to those he works alongside in the laboratory. Similarly the doctor from the HIV clinic doing ward rounds is better paid than others seeing different patients in the same wards. However, for these people top-ups are appreciated. They work hard and are committed to their jobs. At this public hospital such deprivations and inequalities are to be expected. Perks and advantages are taken where they can be, here and elsewhere. Arguments reoccur about whether or not fieldworkers should be allowed to take their motorbikes home, and use them in their free time, for example[75]. Employment, and the achievement of sufficient education to gain such employment, is rare in the Gambia. These professionals are a middle class, across all three clinics. They are also often the only significant wage-earner in their household or compound.

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[75] This is common practice, but was not allowed. A recurring problem here, which was much more serious in up-country clinics, is that of health workers using vehicles out of work, to visit family or friends, then not having sufficient fuel to do their work (or in one case I heard to run the generator). On the other hand workers argued that if they had to use public transport to come to work and return home their work would inevitably be delayed and more limited.

Many health workers of all grades told me that they cannot tell their family what they earn; you cannot refuse the constant requests from the extended family, so to save any money is almost impossible. This clinic is light and airy, with high ceilings. It is also small; with doctors seeing patients in cubicles behind thin curtains opposite the waiting benches. The registration table where patients are weighed and asked about their condition and symptoms when they arrive is at the far end of this main room, again next to the benches where others wait. A further corridor separates counselling rooms; tiny, with blacked-out glass doors, a staff room and toilets. Although cramped this space is functional, and the staff are grateful for it; some of them having worked in worse circumstances previously. However, issues around space and confidentiality are of vital importance to patients, and impact strongly upon their experience of using the clinics, as is discussed in the following section.

HoC is cramped. Within the health centre compound there is no space for expansion and staff here complain that they need more rooms. The building is similar to Gambian homes; separate doors lead into five rooms from an open veranda. To the right a warren of smaller rooms sit next to a meeting room and their small ward. Every space is used. The offices for this clinic are in rented space in a compound around the corner. Walking through the gap between the two buildings takes you through a corrugate gate, straight into the heart of Brikama Market; stallholders pressed up on every side selling food, fabric and other small goods. If you bang loudly enough on this 'back door' someone will come and let you in. Looking back from the veranda of the main clinic towards the waiting area you see the patients from this clinic, those waiting for other lab tests or to have their blood taken, as well as relatives of those in the wards. Often people are eating and chatting. When people are called in their turn their names are shouted across, and people look to see who will go in. Everyone knows HoC is an HIV clinic. There is little inside space at this clinic; unless you are seeing the doctor, counsellor or nurse in their room, you are outside. Only one small area, between the buildings, has a wooden bench behind a curtain for those waiting to see the counsellors. Otherwise this is a very public space. This is a busy clinic, and the staff here work hard. However, here, as with all the clinics, there are issues around those who 'disappear' – staff told me that 'some of us work very hard, but some others can never be found'. This clinic was set up by WEC, a missionary organisation, and as such has a Christian flavour. While WEC funding was

withdrawn and the doctor they employed left the country just prior to the start of my fieldwork, the links were still there. The home based care work they undertake – visiting sick people in their homes, with a team of volunteers – is run by nuns. These two women lived in Brikama and took an active role in the clinic throughout my fieldwork; predominantly with HBC and distribution of items such as powdered milk to mothers. There is a religious flavour to some of the ways in which this clinic conducts itself; particularly on my first visit in 2004 (when such associations were stronger) I was struck by a religious tone – of fire, retribution and rebirth – in the language used by the staff and their patients. However, interestingly, the majority of the staff are, as in the Gambia, Muslims. This clinic is very under-resourced. Aside from GF funding, with the withdrawal of WEC support, they found it difficult to continue; and to meet the ever higher targets set by NAS and the GF, with no increase in resources. At the end of my fieldwork this clinic had just managed to gain NGO status, which would allow them to fundraise, and, they hoped, give a degree of independence from such structures.

As part of an international research organisation, the MRC GUM clinic is, in comparison to both of the others, a well resourced and staffed clinic. The wage structure here is different; top-ups are not given to these staff but they are paid according to MRC wage structures – at a higher rate than government or NGO staff[76]. This does not prevent other staff within the MRC believing that this disparity also exists here[77]. However, this clinic is the busiest and experiences more issues around workload and organisation. This is due to the pressures exerted through the dual functions of research and clinical practice; as described below, the everyday tasks of doctor and nurses' examinations, counselling, testing, taking blood, and recording are time consuming. Added into this recruitment and monitoring, including also pill counting, blood tests and additional counselling for research makes this clinic by far

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[76] In late 2007 NAS realised that they had overspent in the previous year and tried to reduce costs, they targeted the MRC pay structure, trying to persuade them to reduce payment in line with those at the other clinics. The MRC refused. This would have meant that some staff within the GUM clinic would be paid more than others as those paid with MRC budget, as opposed to GF funding would have remained on the same wage scale.

[77] GUM clinic staff on different occasions reported that the ward staff believed this. One incident involved an HIV+ patient who had been in the ward being 'dumped' outside the GUM clinic as the ward staff believed that since the GUM staff were paid more they should take care of 'their' patient. This is unusual in this clinic, although very similar to the behaviour reported in RVTH where ward rounds and general nursing staff regularly bypassed HIV+ patients for the same reason.

the busiest. At the start of my research this clinic had the most patients, and was the most efficient clinic. While the numbers at the other clinics rose (although never to the same number), their day to day practice in general became more routine, and so manageable, while the MRC seemed to lose its way amidst these combined stresses. The original GUM clinic was quite cramped, but connected into the ward and other buildings. When patients registered they sat outside on the small veranda – which became crowded with patients sitting or lying next to one another. Once they were called in they went through the reception area where the records were also stored; wooden boxes labelled by year stuffed with record cards piled high on metal shelves. Moving through this room into the main clinic a central corridor led to doctors' and nurses' rooms, bleeding and counselling rooms as well as a staff room. Once inside the clinic you could wait for your next appointment within this space; observed only by the staff and the few patients also moving from room to room. The staff here were justifiably proud of their clinic and their work. When the clinic moved there was a nominal consultation process with the clinic staff. However, the new building – designed for purpose – was deemed to be unsatisfactory by both staff and patients. This building seemed much larger, and yet there were never enough rooms, and the staff never had a room for their breaks. The organisation of the clinic also meant that patients entered though one door, then either had to wait in a narrow internal corridor or return outside to be recalled through another door. This new clinic, perhaps due to its newness rather than its wrongness, exacerbated existing stresses around systems and waiting times, as described below. Staff in this clinic were also much more dissatisfied than at either of the other two. A system of repeated short-term contracts meant that staff with years of service were potentially insecure in their positions. In interviews most of the staff in this clinic used this opportunity to talk about how their past experience – in many cases great and varied – was under-utilised. One woman, employed as a translator, was a trained counsellor who had worked in other African countries. She was shocked at the standard of counselling available in the Gambia – "this is not counselling" – and frustrated that she could not use her skills and experience. Hierarchy and job description took precedence over experience and, as in this case, common sense. This led to some staff members being demotivated and disinclined to put in extra efforts which were not valued or recompensed. Interestingly this clinic, although it was distinctly non-Gambian and non-denominational, had a disproportionate number of Christian staff. This may be

because educational opportunities in the Gambia are more readily available to Christians[78]. However, this disparity was not noticeable at the other clinics, despite some cross-over in staff over time, implying a relationship between employment opportunities at the MRC in particular and Christianity.

The relationships between the clinics and their patients were strong – particularly with long-term patients, often members of the support groups affiliated with each clinic. However these relationships were not always straightforward. The clinic at RVTH, being the newest, had less underlying tensions. The counselling staff in particular took a strong lead in bringing the group together – it was formed during my fieldwork. The clinic staff happily shared their staff room with the group, where they had meetings until late in 2007. This clinic also employed patients as lay-counsellors, and there was in general a less hierarchical atmosphere in this clinic; both among the staff, and between staff and patients.

HoC had many issues with the support societies; as the members did with each other. During 2005 the support group in Brikama split in two. The leadership of the original group fell out with clinic staff, and for some time said they would not return. Although this was resolved, clinic staff focused their attentions on the newer group. This schism was partly due to tensions and jealousies over resources and opportunities (as will be discussed in the final chapter, support group perspectives), as well as clashes between strong personalities. Those who formed the new group took on an ethos of self-help and group solidarity, in reaction against the previous organisation which they saw as self-interested and money oriented, and supported by clinic staff. However, both groups continued to struggle for resources and support. The relationship between HoC and these groups can be interpreted as ideological. This clinic through the start up of the groups and also over issues around treatment, disclosure and behaviour, gave strong moral guidance; perhaps due to its missionary roots this was ideologically grounded in ideals of community and openness.

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[78] A remnant of the colonial system, most of the better schools in the Gambia are Christian. Many older Gambians (including the previous president) 'converted' taking English names in order to attend.

The MRC, as the first clinic, was affiliated with the oldest support group. This long running relationship experienced many difficulties. However, on the whole members of the support group were proud of 'their' clinic; although the clinic staff and MRC management were not so impressed. Support group members, rightly, felt that their treatment was secure; MRC being better resourced and more reliable than the government. The 'brand' of MRC, while it carried some negative connotations, inspired confidence and a sense of belonging (Geissler et al 2008; Leach and Fairhead 2007). During the early part of my fieldwork the clinic viewed the group in a paternalistic and judgemental way; the practices of accountancy and group management were not seen to be functioning for the best interests of the group as a whole, or in line with ideals of democracy and transparency. Fighting within the group was also a problem. In 2006 a physical fight within the group, which resulted in one woman hitting another with a large metal pan lid, resulted in the groups' advisory board, mainly MRC, intervening. They met with group members and chastised them. A code of practice was drawn up for group members' conduct and activities and copies were printed and stuck on walls and doors around the centre. That most people could not read this document (including the women involved in the fight) did not seem to matter. This incident, among many lesser interventions and the comments of staff, also implies an ideological imposition of values from the clinic to its group, as in Brikama. However, here the values were 'Western' individualism in terms of responsibility and conduct; as well as in relation to issues such as disclosure, as will be discussed below.

6.1.2. VCT and starting ARVs – waiting for treatment

The ARV treatment programme is shaped by the requirements of patients, staff, the clinic structures within which they work, and the requirements of donors and other agencies, particularly in reporting and recording. But the benefits of ARVs are undeniable, as described earlier in chapter three, bodily spaces. Both staff and patients make comparisons with the 'hopeless' situation before treatment arrived and clinical interactions since the advent of treatment;

> As for when [I found out] I was HIV+ then there were no ARV drugs available in the Gambia. They only tell you about your status and then finish with you; it is only left with your courage. Now that someone is tested HIV+ and will be told 'here are ARV drugs' so it is left to you. This means that the

person has hope, unlike before. If you lose hope even though there are ARV drugs available then it means you don't like your life because there are medicines that you can take to help you.

<div align="center">HIV+ woman speaking in MUTAPOLA women's network meeting 2007</div>

When a person enters an HIV clinic as a new patient in the Gambia they enter a mystifying world of numbers and measures, drugs and tests. The trauma of an HIV+ diagnosis, and the anticipation of a positive test result is a major factor in people's responses to the clinic, and can cause them to 'run away'. Losing people who do not return to find out their diagnosis after testing is an ongoing issue for the ARV treatment programme;

> Sometimes if I used to run away they follow me up to my home. First I came to the clinic without my status but when they checked my husband they found out that my husband has the virus which kills him, and that's the one I also have. That is why I feel afraid because of the HIV – I watched.
>
> HIV+ woman, workshop discussion, December 2007

> Sometimes people are afraid if are told by the doctor that you are positive. If he told you to come on the 5th you may likely to fail thinking that whoever visits is infected.
>
> HIV+ woman, workshop discussion November 2007

The process from one clinic was outlined to me in 2004 by two nurses, as they prepared to begin ARV treatment with their patients. Their description illustrates the complexity of their task, and the crossovers between the clinical and the social. It also demonstrates the constant negotiation which occurs around processes and procedures to which people are required to submit, as well as the sensitivities dealt with daily by these front-line workers;

Patients come to the clinic from other health clinics; private clinics as well as other hospitals and they arrive with a referral paper. Or they come because they are sick, or they are referred from the other clinics.

They come early, and we put their papers in a pile as they arrive, so they are seen in that order. Then the papers are given numbers, we don't separate old and new patients [in ordering them by number]. But we do then separate the to-be-registered

patients from those already registered, if they are old patients they look for their cards, which are kept here, they take home a card with only their name and a number on it. They weigh and take the temperature of new patients so this can be entered on the database.

There is an interpreter for each doctor, and they come to call the patients in. New patients can see either a nurse or a doctor, if they are already diagnosed HIV+ they see a doctor. If they only have an STI they see a nurse, if it's not so busy they would see the doctor. The doctor examines them and takes samples, but not blood. Then if they need they are sent through to the counsellor.

They [the counsellor] inform them about the HIV screening, and the patient decides whether to consent or not. They check the patient's name against the form to make sure it's the right one. They tell them the purpose of the meeting, inform them about what is HIV. First it's important to test their knowledge – asking questions like; do you know what is HIV? Do you understand HIV? Have you heard about HIV? You can phrase it different ways. And; do you know how it's transmitted? Then you go on to the pre-test counselling.
...
Most people know about HIV, from the radio, or from other people, but they don't know the detail. They only know sex, a few know needles, and most people don't know MTCT. More educated people can tell you three routes, most people sex and injections. Almost everybody has heard of HIV…

Some people very badly don't want to know their status, they don't want to know, they are not interested. Some say 'I don't have [HIV], but Ok'. Some are afraid to know their status. Some feel they cannot have it, including Muslims and Christians, especially born again groups they say 'God forbid! I'm not involved in this'. But when you counsel them and say it can be from before you were married, and they think back, you can see them thinking, if they had other partners before. Others again say, 'I'm sick, I just want to know what'. Only 2 or 3 in 10 people say no to the test.

There are difficult days, when there is a lot of denial. We think, we don't know, but our theory is than they communicate outside. Especially if there are people there from

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the same place, and once one says no, and says to the others then everyone says no. They [counsellors] do it anyway, ask, and ask again, and ask again, then after that ask for their reason and write it down.

Then they[the patient] go to the bleeding room and have a sample taken, and they are given an appointment, and their address taken, then they go to collect any medication they are prescribed. The social history form is filled in at pre-test, not everybody does this; if patients OPD [Out Patients Department] number ends in an even number or zero then they do it, not everybody, so there is a random selection. They always do the social history form before the counselling, as if they counsel first and talk about transmission then ask the number of sexual partners they won't say, so it has to be done first, otherwise none of them would do it. There are some who are sensitive about answering the questions, most accept though; very few say no, they can say yes to the social history form and then no to bleeding.

We looked at the forms together, I asked about which were the hardest questions to ask and which ones people didn't answer [there are 2 forms – one for men and one for women].

The final section 'health sexual history' is the most difficult. Asking about circumcision for both men and women is very difficult, as this isn't something people like to discuss, it is secret, an area people don't want to talk about, especially old people. Asking if they have ever had sex for presents or money is very difficult, again for both sexes, women will say 'is that possible?' the 'commercial girls' will say yes though. Men, when you ask if they have ever had sex with a prostitute, they'll say 'maybe, I don't know, she didn't tell me she was a prostitute'. The hardest question for men is the last [they seemed a little reluctant to say it to me – I read it out – sex with men]. This is very hard for Christians and Muslims; they say 'is that existing?' When asking for the number of sexual partners many people refuse, or they say, 'I don't know, you pick a number' sometimes they give any number. It is very difficult for us, especially with the elderly, as we should respect them, with 'fanatics', and with teenagers, as they are very shy, we say, 'we are sorry for asking, but it's because of the work.'

When they come to get their results, when they come in, as before, and when it comes to finding their card we can see on it if they are positive. We weigh them and take their temperature and enter the information. Then they go to see the doctor, the doctor tells them the results have returned and that they will see the counsellor to find out. [One doctor] will inform them himself, others send through to the counsellor.

This can be very difficult with patients from other clinics, at the OPD they have pre-test [counselling] here, at other clinics they have no pre-test counselling, some people don't know they've had a test, they don't inform patients properly. Sometimes a patient will bring an envelope to the clinic, but they don't know why, and in the envelope is the positive result.

Some patients, when you tell them they accept, but some are sceptical 'why is it me?' especially those who are newly married, or who are only married to one person. They can't understand why.

In post-test counselling first we interview patients, to see if they remember the pre-test, and if they remember agreeing to take a test. We ask what they expect, and remind them of the information from pre-test. Then they ask if they want to know the result, it is not common at all to say no at this stage, although sometimes they do refuse in pre-test, they say take the blood but I don't want to know the result.

It is too soon at post-test [to discuss disclosure], they need to get used to the result, get used to knowing themselves, maybe after 2 or 3 times they will start to talk about telling someone else. You can't tell them at the beginning, it's too hard, after a few visits, then you can start to talk about it.

In post-test they[patients] need to ask questions; how long do you think I'll be alive? Can I get married? Or; can I have children?

At this time we also tell them about ARVs, and the possibility of treatment, tell them how they work. Many people understand that there is treatment in Europe. Some don't know it doesn't cure, so we must explain. We stress adherence and choosing low CD4 to select patients, we must inform them that this is lifetime treatment. We don't

say much about ARVs, as it is just starting, if we say a lot the patients will think it is for everyone. We tell patients it is not us who decides, it is a selections committee.

Sharing confidentiality is not easy, in the Gambia most people think HIV is from sleeping with many people; prostitutes and playing around. So they think if they tell their family they will think this. Some say 'it's better for me to die than to tell my family'. A few think they'll be 'left out' by the community, due to the ideas of what kind of people have HIV, they think they'll be left or abandoned, that people will see it as a punishment. One teacher, who tested positive, and people came to know. If she had some bananas, and she went to hand one to a child, they wouldn't take it, she couldn't hand something to anyone. She had a short life; she could not cope. She felt like dying. People didn't want to be associated with her, wouldn't share anything with her; bedding, food. She was always lonely; people wouldn't even sit and chat with her.

Stigma is a big part of patients' response. You can see the difference in people supported at home, and those who are not. Those who are supported look healthy, unlike those who are isolated and stigmatised.[79]

At the time of this interview the ARV treatment programme was just beginning, the eligibility committee was in the process of being formed, and the conditions for starting treatment finalised. However, this process, the complexity of seeing different nurses, doctors and counsellors on each visit continued, with similar structures used at the other clinics.

Over time, the volume of patients and the burden of reporting paperwork from the GF impacted on this, making waiting times even longer. For health workers the paperwork burden, and for each clinic the different burdens of reporting to different structures as well as the GF, with different frameworks, timescales and information wanted, was often discussed. The GF reporting procedures in particular were seen to be too exacting – counting people, tests done and drugs given and reporting monthly.

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[79] Adapted from interview notes, interview with two nurses at HIV clinic August 2004 (initial visit to the Gambia)

The complexity of clinic processes, coupled with reporting demands on health personnel translated into long waiting times for patients. Staff told me that they tried – especially for those (few) patients with regular jobs – to see them quickly. However, from the patients' perspective waiting times were often a problem, which could cause problems at home due to questions about extended absences;

> What could help [people come to the clinic] is that there should be effective counselling and doctor should always try to attend and treat them quickly so that they have their medicines early. Because in most cases people go to the clinic as early as 5a.m. or 6 a.m. and later has to come back home by 4p.m. or 5 p.m..
>
> HIV+ man workshop discussion, December 2007

Staff too found the waiting times a serious issue, related to both the patients' experience and their workload;

> There are so many problems in this clinic now. So many problems! Sometimes we are here from eight up until eight.
> *Maybe you need more staff?*
> No! There are enough of us here, we don't need more staff. Even if there are 10 or 100 staff the problem is the same. The system we have now takes too long. We have so many problems here now. Maybe it [new system to be introduced around post-test counselling] will make it quicker, but I fear it will make more work. Now there is no recognition and no remittance for all these hours…
>
> Health worker, in conversation, August 2007

Often people arriving early in the morning would still be waiting after lunchtime, many until the end of the day seeing one staff member then another. Staff often spoke about the difficulties these people faced, and how they wished the process could be improved. The MRC clinic in particular had many problems, as the dual functions of HIV clinic practice and research clinic recruitment and surveillance weighed heavily on staff time, increasing the number of people each patient would see per visit. Patients were often confused as to which parts of this process were parts of treatment and which research.

Waiting can also be a time when people feel exposed; patients from all of the clinics stated in workshop discussions that the waiting area was the most uncomfortable area in the clinic for them.

> The uncomfortable areas are at the waiting room because many people first met there and curiously looking at each other to know what kind of sickness you may have, and the ward where someone is admitted whenever the sickness gets worse.
>
> HIV+ man, workshop discussion, December 2007

> The waiting hall [is not comfortable] because whoever sees you sitting there thinks that you are HIV patients.
>
> HIV+ woman, workshop discussion, November 2007

> Because everybody knows MRC and if they see you they start talking some point fingers on you
>
> HIV+ woman, workshop discussion, December 2007

Similarly, although extra support is helpful it can add to fears that people have of being exposed in wider society;

> If you go to the clinic and explain your problem you are sometimes given other supports like buckets, soap and other household materials. If you get home people start asking 'where did you get this from?' If people should think of this they will die immediately. Even pregnant women it is difficult for them to visit the clinic because of stigma.
>
> HIV+ woman, workshop discussion 2007

One of the clinics used a certain type of plastic bags to distribute support to HIV+ mothers; milk powder and other products. However, many people felt that the bags were an instant signifier of their status, and that people leaving this clinic could be identified. Once the patients raised this issue the bags were changed. Such concerns are important as they represent the ways in which relatively minor clinic practices may spread into the wider social sphere. They also illustrate the sensitivity that people living with HIV feel. These are environments which they are accustomed to, and can read with ease. Some people who attend the clinics regularly can explain, for example, that if they see someone going through one and then another door, then they are positive – reading the clinic procedures to recognise a positive diagnosis,

watching from the waiting area. However, others without this knowledge would not be able to make such connections. This does not stop people living with HIV from feeling insecure and potentially exposed.

Within the clinic people living with HIV are at once in a bounded and defined biomedical space, but they also remain within a wholly recognisable and accustomed space; waiting with others they may know and with relationships with others in this space. This duality, the pourousness of the clinical space, comes through in peoples fears around exposure. This may be a contributory factor in poor clinic attendance. Asked why 'some people might miss appointments' this factor was brought up many times, among other issues;

> First of all I think the individual him or her self did not want his or her life.
> Or others it is because of stigma and exposure. Some others fear taking their blood because of MRC is suspected of taking peoples blood to sell them.
>
> Some people feel that they are ok now so there it is not necessary to be going to the clinic or if there is no pain in their body. Other reasons are if someone regularly goes to the clinic then later people might wonder what type of disease or sickness is with them for going to the clinic.
> HIV+ men, workshop discussion, December 2007

> [people might not want to go to the clinic] because of stigma and what people might think
> HIV+ woman, workshop discussion, November 2007

> Because of finger pointing and feeling shame
> Because people talk behind you and say she is going there
> HIV+ woman, workshop discussion, December 2007

> Because of exposure, [they] don't want to come out
> Discrimination, being isolated or keeping aside
> Some are afraid
> Some people feel shy to go to the clinic because of how people think of HIV
> HIV+ women, workshop discussion, December 2007

> They don't want to be seen by people
> Some people would not like to reveal their status
> HIV+ woman, workshop discussion, January 2008

The procedures of ARV provision, and the time they involve, can thus be seen to shape peoples experiences of using the clinics; their fear and discomfort and so also their willingness to potentially be exposed through attendance. However, it is also through these environments that people come together – meeting others who are HIV+, often facilitated by the staff. These waiting environments can be productive in this way, although the issue of disclosure is always there, as one health worker described;

> Each facility has the means to bring people together, and they interact very well together…. They know not to ask each other "Oh, are you this too?"
> Health worker speaking at staff training, September 2007

6.1.3. Disclosure – who to save?

As treatment became a reality in 2004 many practicalities had to be worked out. Among these the most debated, and contentious, was disclosure, as in the account of one staff member;

Within this debate there are two poles, [missionary doctor] with the view that it should be compulsory and MRC with the more western high-confidentiality model.

It is the case that if you have support, you adhere and you survive.

When you give away ARVs should you accept someone who has not disclosed? Should we not 'save' those with the highest possible potential for success?

The eligibility committee avoided these issues. I had envisaged a discussion of factors and how to weigh them against each other, social and medical issues, in what is a 'no right answer' situation; but this was not done.

The committee has met twice… [but] there are no centralised guidelines…

There was one situation at the clinic here where patients got the impression from [a nurse] that disclosure was required, she denies that she said this to them, but in the end it worked out well; many of them did disclose, bringing a family member. And I don't think we lost anyone.

But the national guidelines now are somewhere in the middle, with all the centres taking differing perspectives; at Brikama they are talking about it being a requirement. ... patients who are exposed to MRC's stance tend to take this on board, whereas those who are at Brikama, where Dr X was working, were exposed to this opposite position and are more accepting of disclosure as a prerequisite to treatment.

Adapted from interview notes with health worker MRC GUM clinic August 2004

Different people in positions in clinics, government, NGOs and Support Societies took different positions with two poles; privileging the individual and their rights, or privileging a public health position which demands that partners be traced, notified and tested. Such differences did not only exist within clinical decisions. As one NGO worker described his frustration to me;

> It is difficult to work with these people, living with the disease. It is always about their rights. They see things differently, you talk about something and they just talk about their rights.
>
> NGO worker in informal discussion, July 2006

The next chapter takes up further discussion of how such concepts and language spread out from the NGO partners and also, as here, the clinics, to inform the understandings of people living with HIV themselves.

The move to treatment was both a huge jump forward giving hope to people who before had only treatment for opportunistic infections and antibiotic prophylaxis (septrin[80]). In anticipating ARVs people already had experience which taught them how medications can act within the home;

> Long before I disclosed, my father saw my drugs. Six packets! Big packets of drugs all on the table, and my father said 'why are you taking all these tablets?' [Laughing]… I said 'oh... you know I've been ill, I'm taking them for that' but he couldn't understand why there were so many, I swept them away into my room, and he never saw them again, never saw them again from that

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[80] Septrin is the trade name for this drug (co-trimoxazole), however, this is the name used by the patients who took it. Many people told me they took "septrin, multi-vitamins and *buffrin* [ibuprofen]" provided by the clinic.

day. Until I disclosed to him, and then I could say, you remember all the drugs? Well, they were for that… I can laugh now, but I was scared, just swept them all into my room.

<div align="right">HIV+ man, support group member,
speaking during initial meeting with Support Society August 2004</div>

While at first there was a noticeable difference between the two main clinics in people's attitudes to disclosure, which I interpreted as being related to the different ideologies espoused by, and religious undertones of these two very different organisations – as described by the physician above, by 2006 the differences were moving towards resolution and disclosure was a condition of treatment, one which some resented and others understood. Disclosure remained, throughout my fieldwork, a very contentious issue. People had very mixed experiences, and felt different levels of support from the staff at the different clinics. Over time, and through conversations with staff and their patients in different environments (clinic, support group, and elsewhere e.g. meetings or trainings) I became aware that some individuals gave different accounts of their families in different circumstances. As described in the previous chapter, such 'lies' were judged harshly within the clinics. This discussion, about a man who was threatened with 'expulsion' unless he disclosed between clinic (C) and CBO (B) staff illustrates the high tensions around such situations, and the expectations placed on patients in return for treatment;

> C – The man will ignore the end-date and carry on regardless, and once it is too late and he's run out of meds it will be a big scandal, and everybody's fault but his own. Then he'll claim racism and prejudice and infringement of his rights.
> *B – yes [laughs] he said to me 'I'm a Mandinka and we don't discuss our personal problems with anyone'*
> C – well, we should tell him if you're a Mandinka then fine – take your Mandinka medicine and don't discuss anything with anyone. But this [ARVs] isn't Mandinka medicine and if he wants to take these they come with expectations…

As with many elements of HIV treatment, these decisions are very personal and difficult. However, here they become in some senses routinised and medicalised; often disclosure to close family occurring within the clinic environment and as part of the route to treatment.

6.1.4. Counselling

As some parts of the treatment process can cause discomfort, others can create a comfortable and safe environment within the clinic. Prior to treatment, but more urgently as funding was gained and the ARV programme took shape, the correct procedures around VCT – voluntary counselling and testing – were introduced in the Gambia. Such clinic practices and the 'correct' procedures are a clear illustration of the implantation of the 'global assemblage' at work. Counselling was not – and is not – provided as part of any other health care intervention in this context. This in particular was a new form of interaction – for patients and staff. Counsellors were varied in their experience and training; most were counsellors and nurses, or counsellors and fieldworkers. A few were hired as counsellors or 'social workers', but there are no specific qualifications for appointments. The only training for counselling was in-country, provided by NAS or NACP, or later with the different partners (clinics, NGOs and government) training each other based on their experiences. Counselling is, in this context, primarily about information transfer; giving information to the patient, and checking that they retain it. How effective this is – either as a psychological support or as an instructional route to better adherence – is variable. The counsellors I interviewed were proud of their work, and passionate about supporting their patients, despite the heavy workload and emotional cost to themselves. It is however, also possible to view these relationships as paternalistic; as coloured in some circumstances by a charitable helping of the less fortunate, rather than as clinical relationships.

Counselling is often spoken about and valued by patients; all the discussion groups giving the counselling room as the first response for 'comfort' within the clinic;

> The comfortable areas are the counselling room because you are there with the counsellor, only two of you and to be assured about the sickness…
> HIV+ man, workshop discussion, December 2007

> [You feel most comfortable] in the counselling room because if you are tested and found to be positive they talk to you on how to go about it. If you are married they will tell you how to approach your husband.
> HIV+ woman, workshop discussion, November 2007

[The most comfortable room is the counselling room] Because if they don't talk to you, you cannot know how to go about your treatment
You cannot know how to take your drugs and drink [them]
You cannot know the reasons of taking the drug
If they talk to you then you will know how to go about the treatment
                                    HIV+ woman, workshop discussion, December 2007

The counselling room [is important] because that place they counsel you to have confidence and to reduce your thinking about the disease

[The most comfortable is the] counselling room; you sit privately with the counsellor and he helps you in counting your medicine and sometimes when you have stress he will tell you to forget about your problem
                                    HIV+ woman, workshop discussion, December 2007

Counselling room helps people have a free mind so they will not think of the virus
                                    HIV+ woman, workshop discussion, December 2007

When I was told about this I cried bitterly, and Dr.X told me that there is a support group going, and this would really help you. I then went further, went for further counselling…
I feel differently now, and I now have to decide what I should do for myself. My brother wants me to get married now but I'm telling him no, because I know that marriage will not help me in the future
                                    HIV+ woman interview October 2006

On the whole these relationships were positive and supporting. Many people spoke about the ways in which their counsellors had helped them; to 'accept' their diagnosis and also to disclose.

The form which counselling takes is primarily through information transfer – to give information to the patients as to how they should behave, around drug adherence and also sexual behaviour, protecting themselves and others. The ethos of these interactions is individualistic; the information and actions of the individual being the primary focus. However, these are also social, with long term bonds built up between client and health care worker. As these relationships go on people are also able to discuss the difficulties they have. One role of the counsellors is to facilitate disclosure, and often people will bring their spouse or other relatives to the clinic so that the counsellors can disclose for them. When such encounters go well the sense of

relief for the patient, also adds to the bond between counsellor and patient. For many in the support groups there is a great loyalty and sense of belonging to 'our' clinic, often also to the specific individuals who helped them through this traumatic process.

It can also be the case that people feel that the clinics let them down in this relationship, and fail to meet the standards of confidentiality they introduce, and lead their patients to expect;

> I would like to say one thing about counselling especially at [X] clinic in [place]. The counsellors there do not mind to keep our secrets and we the patients feel very uncomfortable and disrespected anytime we visit there because even our registration book is put outside in the waiting hall where whenever you come they just tell you 'go there, on that table and sign your name' those are not the kind of people who should be counsellors especially on HIV/AIDS because they don't have the attitude and behaviour, moreover, the empathy. We were hoping to have a meeting where Dr X and Dr Y may be present so that we can complain to them as people living with HIV are facing difficulties and sometimes feel harassment at some clinics, so that they can help.
> HIV+ Female, speaking at a Mutapola (women's network) meeting 2007

Counsellors struggle under the weight of their task. For every new patient pre-test and post-test counselling, and for every returning patient, particularly those on ARVs or preparing to start, counselling to reinforce messages around adherence and disclosure. Under these circumstances structures can sometimes falter – for example records with names and status being revealed in public places. In this context where people feel their status can easily be revealed this can create problems and further fear for patients.

6.1.5. Adherence

Adherence is a major factor in prescribing ARVs. Near perfect adherence is necessary to ensure that people do not become resistant to the drugs they are taking. Second line therapy was not available until late in 2006, with limited availability and potential problems of cross resistance. Staff in all clinics give a strong message that adherence is key to treatment success, and that family support and disclosure is key to achieving this. Although there were initial problems with accepting the necessity of disclosure

in as a condition of treatment access, many patients actively take on this idea, as discussed in the previous chapter;

> If for a woman the husband needs to help [to take drugs on time] and for a man the wife needs to help. But in some cases the husband may not know so the best people to help are your mother sisters and the ones you trust.
> HIV+ woman workshop discussion, December 2007

> It is not easy at all [to take ARVs] as for my case because drinking medicines is not easy each day, but because of your health one has to take them.
> HIV+ man workshop discussion, December 2007

Asked why people may not adhere to their treatment people at once recognised the psychological difficulties of being diagnosed HIV+, as well as the importance of 'believing' in the treatment;

> They don't love themselves
> They don't have the belief
> HIV+ women workshop discussion, December 2007

Thus ARV treatment is moved from a realm of 'simple' biomedical or chemical process to a space of 'belief' where people must have faith in the drug and it's processes. As discussed in chapter four people have recourse to a variety of treatment options, clinic-based medicine one of them. For other types of treatment 'belief' is important, an idea which appears from these statements to also be applied to ARVs. Clinic staff also discuss "how to measure [people's] belief in these ARVs – in terms of preparedness, in terms of acceptance" with reference to the post-test and pre-ART counselling processes.[81]

As discussed in Chapter 4, bodily spaces, the difficulty of side effects and symptoms, coupled with a lack of food, also affects adherence. Financial constraints and a lack of symptoms can also cause people to miss appointments;

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[81] Health worker, speaking in clinic staff training February 2007

> Sometimes it is lack of fares and will feel shy to explain this to someone to help him or her with fares. Some, if the person is not seriously affected. Others don't want to be blamed by the doctor and be seen as someone who is not serious on the treatment, with others it could be that they don't want their own health and life. Some people do not want to be labelled and stigmatised.
>
> HIV+ man, workshop discussion, December 2007

As Hardon et al (2007) also found in Uganda, Botswana and Tanzania, financial constraints around the treatment process, hunger and other side effects, and the difficulty of taking drugs around people to whom one has not disclosed are the three major impediments to adherence.

Discussing why some people might not report missed drugs to the clinic staff a repeated theme is 'blame', illustrating the power relations inherent here, through the ways in which people are subject to medical surveillance;

> Because if they know they will talk because any drug given to you they count and if you fall sick and they take your blood they will know that you didn't take your drug
>
> HIV+ woman workshop discussion, December 2007

> If you go to the clinic you will be blamed
> You will not be given drugs
> You will become seriously ill
>
> HIV+ woman workshop discussion, December 2007

> If the clinic knows you may be blamed for not taking drugs
>
> HIV+ woman, workshop discussion, December 2007

> They don't want to be blamed by the health personnel
>
> HIV+ woman, workshop discussion, January 2008

These comments underline the unequal power relations in the clinic environment, and the inherent judgements which people feel within these relationships. The duty to do as instructed is keenly felt as well as the sense that you will have undermined a reciprocal relationship – your responsibility, as outlined in counselling, in exchange for the drugs you receive.

Support for people in adherence to drugs was positioned strongly within a discourse of personal responsibility, and in relation to disclosure to a 'treatment supporter'. This shows echoes of the travelling discourses of 'good' HIV practices, as discussed in chapter three – Global Spaces, and as Nguyen also notes;

> These strategies were a hybrid of approaches pioneered by communities affected by the epidemic in Northern countries, which drew on local forms of solidarity to organise "buddy" systems and support groups… the "buddy" system of therapeutic companionship – pioneered by the North American gay community in the early years of the epidemic.
>
> 2005; 127

The treatment buddy system introduced in the Gambia also illustrates a broader tension between public health precautions, in contact tracing – testing and treatment for partners and sexual contacts – and ideals of individual rights to disclose. The necessity of disclosure in order to access treatment was contentious from the start – many people in the support groups discussing the difficulties this created for them. As discussed in the previous chapter, many women in particular complained that absent or unsupportive husbands were not 'supporters', and they should be able to disclose to fellow group members who better understood their problems. Many women described how these forced disclosures had resulted in unsupportive home environments; with family members not only unprepared to remind and support drug-taking, but actively discriminating against them. As time went on, and people within the groups experienced both these negative and also the positive experiences of disclosure the fear lessened, and the relationship between disclosure and treatment became more widely accepted – although generally the necessity of disclosure to spouse as related to adherence was less experienced or accepted.

Here then, adherence to treatment is affected by local practices and understandings, as well as by the culture of the clinic with its daily practices informed by both the global and the local, rather than any particular 'culture' of the Gambia.

6.2. Talking about treatment

As the previous section described clinical practices spread out into the world – the staff and patients are both in the clinic and in the Gambia - with the relations,

hierarchies and pressures both of these interlocking 'spaces' imply. The language, metaphor and discussion of HIV in the Gambia have also been raised in earlier chapters: in chapter one I discussed the global discourses which are enacted in the Gambia, as described also in the previous section, and which inform these clinical practices. In chapter two I showed how bodily space is interpreted through metaphors of 'body soldiers', CD4 counts and viral loads, measures which are created within the 'clinical' space, but which were effectively co-opted by the president as justification for his 'breakthrough'. In chapter three I explored the ways in which understandings of HIV based on biomedical understandings found through clinic based processes and relations spread into the domestic space and interact with competing understandings of what it means to be HIV+, to disclose and to experience discrimination within the home and community.

The clinic therefore, is a generative space – one in which people are given a painful and difficult diagnosis which they then take into the world. Here I focus in particular on the language and discussion of HIV, the ways in which such messages are given and meanings discursively created; the bodily experience of being HIV+ transformed into part of a comprehensive system of understanding. As Mattingly argues, "Therapists and patients not only tell stories, sometimes they create story-like structures through their interactions" (1998; 2).

This section outlines the process of negotiation which took place within ARV clinics from January 2007, after the president's announcement of a 'cure' for HIV. The stories which people living with HIV were accustomed to by the end of 2006 were biomedical – positioning HIV as amenable only to ARV treatment and clinic-based medicine. From 2007 this was publicly questioned; by the president and the ministry of health.

6.2.1. Biomedical space – translation and negotiation

HIV treatment in the Gambia has always trodden a path of difficulty and silence. To talk openly about sex, particularly intergenerationally is difficult. As the nurses' account of a clinical interaction in the previous section highlights, so many questions are difficult and awkward. In trainings the presenters – doctors or other staff from within the programme – stressed the need to listen to patients, to 'hear them' and to

insist on answers to difficult questions. They stressed the use of euphemism as appropriate in this context – "ask them "when did you last see your husband?" – miss out the sexual"[82].

The workings of the clinics, the meanings they produce and the processes they use have always privileged a biomedical framing. However, as Bierlich discusses the use and of scientific language and concepts does not necessarily translate into acceptance or understanding;

> Biomedicine may be attractive, however by introducing its scientific language, concepts and technologies, it may also force people into submission. People become obedient and say what is expected of them, without really understanding (or caring to understand) the implications of the germ theory, disease prevention, or diseases that can only be diagnosed with the aid of the microscope (worms, parasites in the blood)
>
> (Bierlich 2000; 712)

The use of biomedical language is commonplace within these environments. As described in chapter two, the measures used to treat and to talk about HIV are generated here and taken up and used (or misused) to understand HIV and its treatment. The ways in which such information is given and received within these environments is part of a complex set of relationships where the relatedness of the health worker and patient – through language, ethnicity, 'Gambian-ness' – are equally as relevant as the hierarchical institutionalised relations produced within these settings. Some of the ways in which HCWs 'translate' questions and information illustrate their experience of these conflicting relationships;

> If a person is convicted of stealing and the judge asks, 'How many times have you been stealing?' What will you say? We need to find a nice way to ask the question, to find a way. Some will think you are judging, blaming. Make it clear why we need to know. What we feel the patient will answer might not necessarily be the case, for example that an old woman will not be drinking alcohol. So we must try.
>
> Health care worker,
> speaking during staff training in one clinic February 2007,
> Discussing asking questions about the number of sexual partners a person has had

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[82] Trainer (HIV physician) speaking during question and answer session at ARV staff training September 2007

Within this negotiation there was some cross-over between roles; by the end of 2007, in two of the clinics the patients- as-expert were employed to a limited extent as counsellors;

> The moment you tell someone that you are positive, in that instance, he feels fear and starts thinking many things at once. The last is to get angry. So that makes it difficult for some of us to have a good discussion of what they are going to do next. So please, counsellors, try and work some of us in counselling rooms whenever you are giving positive results, let it be said by someone who is positive. And they can say that I am living with the virus of HIV. Then he will listen carefully and will need much information from you. That information will help him more than anything else.
>
> HIV+ man, written account, 2007[83]

The staff in the clinics understand the liminal space in which they work – they themselves changing between their home environment and behaviour – and the practical difficulties this raises in their work;

> The atmosphere is different in the clinic and at home. Here we speak in English. In Mandkina there are different words, in Wolof there are different words. This is where the problem comes. If I am a Serehule, counselling in Mandinka, so this information is interpreted by the counsellor, from English, to the local language, then the patient reinterprets, and then interprets to the treatment supporter. We need to hear from the supporter that the right information is interpreted, and then re-counsel and re-disclose. Ask the supporter "why are you here?"
>
> Health care worker,
> speaking during clinic staff training discussion February 2007

Within the clinics there was always a discussion of how to translate for people the concepts and descriptions of HIV and treatment "it will remain a confusion"(ibid). Through 2006 this was a difficult process, talking about 'body soldiers' and invasion, but "no one knows what the immune system is" (ibid). This was difficult as health workers all agreed that the concepts of 'treatment' and 'cure' were often the same word in local languages. Thus idioms were important;

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[83] Extract from the life story 'My name is Mustapha' written by an HIV+ man active within the groups in the Gambia.

I say, 'its like someone holds my throat and then they let go'
You put your foot on the virus, but the minute you lift your foot it comes up
That sickness was there before, it's not because of the drug [IRIS]
The soldiers of your body
It gets the virus where they hide
It is there, only the machine cannot see it [undetectable]
Health care workers, speaking during staff training February 2007[84]

Issues of translation and how best to relay information are not a one-way barrier to understanding. While people may feel open to 'blame' and sanction for not following instructions, so they also negotiate within constrictive questioning and instructions, maintaining their privacy and ability to make decisions; as discussed above giving partial truths or different versions of the truth in the clinic and elsewhere, often according to what is the 'right' thing to say either for this environment, or in order to access drugs. Often both sides are aware of the 'game' that is played. A discussion around counselling patients and using contraceptives illustrates this;

HCW – People hide. They won't say they use family planning.
Doctor – But we are their HIV clinic for God's sake!
HCW – It's because we say safer sex or no sex they say 'what would we be doing with this family planning?'
Doctor – it comes down to the closeness of the patient and counsellor, the relationship with the clinic…
Conversation during clinic staff training February 2007

In these negotiations the ways in which different worldviews collide comes into perspective; the clash between 'local' and biomedical in language, description and practice. Even as counsellors, through 2006, worked within an effectively de-pluralised public environment and stressed the importance of not using 'local' treatments in combination with ARVs, they were equally aware of their use. Similarly while they counselled disclosure to partners, they were aware of the fraught nature of such disclosures and the potential lack of fit with such proscriptions and their stated aim of support. Within these spaces there was never any discussion of the possibility of using other treatments, however in January 2007 clinic staff and their patients entered a very different set of negotiations.

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[84] Idioms repeated by HCWs to illustrate those they had used, to share with each other and agree. IRIS – Immune Reconstitution Inflammatory Syndrome; when some patients start treatment their immune system reacts negatively. Severe side-effects are experienced, and for some this is fatal.

6.2.2. Changing Spaces – the 'breakthrough' in the clinic

When the president announced his 'cure' for HIV he created a new, alternative, clinical space. His 'cure' programme, had its physical space in Serrekunda hospital and the statehouse. Although I could not observe these places I visited the Serrekunda hospital on one occasion, and spoke to people who were resident and who visited and witnessed or who were themselves 'cured'.

In Serrekunda a new hospital of several buildings, was occupied only by those being 'cured'. In the beginning some Cuban doctors were involved in the treatment, although they were not there when I visited (just after the second batch of patients entered treatment). There were no nurses, no medical personnel; the president was their only doctor. Every evening the patients went to the statehouse to be treated, as outlined in other chapters, with herbal rubs and a drink. Bananas played a large part early on, but later were not mentioned.

These treatment spaces were also very public. Every night the treatment was shown on the only television channel. The newspapers also wrote each day about the success of the 'breakthrough'. Everyone on the country was aware of the president's 'cure' – as it played out like a soap opera, and they came to recognise the characters.

He also immediately implicated the clinics in his own procedures; no one could be treated without a letter from their doctor as 'proof' of their HIV status. For clinic staff and management – across the RVTH (Government) clinic, MRC and HoC – this meant that trained medical staff who had previously dedicated themselves to not only educating people about HIV, what it meant and how the treatment worked, were now asked to somehow endorse their patients' 'default' from this orthodoxy.

Clinic staff were accustomed to discussing the need to avoid combining different treatments, due to the possibility of adverse reactions; or that the ARVs would not work. The president used the same argument.

Despite their involvement in the clinics – their relationships with staff – and involvement in many NGO activities around treatment awareness, many of the group

members during this early period were quick to ask of the president's programme; "maybe it's the same as ARVs". Equally many were moved to forcefully deny the possibility. Perhaps surprisingly it was often illiterate women who were most strident in their denial of the efficacy of the 'breakthrough' and were also able to speak easily about the differences between being HIV+ or HIV-, as compared with the president's claims to a 'proof of cure' based on the CD4 counts and viral loads of his patients. Group members' reactions to the treatment were, in this initial period, based predominantly on the experiences of their friends and fellow members;

> They were on TV last night from ten until close [around midnight or 1 a.m.] last night and they didn't look happy. They were talking but I see them, and they are not happy. I know [one of the patients] …is talking but not smiling. I know they are not happy.
> Informal discussion in support group, February 2007

One difficulty faced by both the president's patients inside and others in the groups outside is that of disclosure – linked to the intense media coverage of the 'cure'. For those inside there were many difficulties; for those not or partially disclosed who did not realise that they would be broadcast nightly on television, forcibly disclosed;

> It's a big problem for these people. When they come out everyone will know. And people will point, how can they hold their heads up again? And they have children, they'll be at school with other children saying 'I saw your mother on TV, she has HIV' and pointing at them. A lot of trouble will come from this.
>
> But even us, they have big problems but we have small problems from this. Already people are calling me saying 'I saw your friend on TV, she is one of those who has HIV', I say 'I don't know anything about this, she never told me, why would she tell me this?' But you see now, before they weren't looking at me, and now they are looking.
> Informal discussion in support group, February 2007

As discussed in chapter one the financial security of people living with HIV was linked to GF-government and NGO programmes. The following chapter discusses the role of support societies in this web of international funding relationships. However, such links to income and patronage, linked into clinics and biomedical understandings of treatment, had towards the end of 2006 become insecure. In comparison links to the president and the resources he could bestow upon favoured individuals became potentially more appealing.

Although NGO programmes and funding were faltering and such interventions much less visible in this suddenly dangerous political environment, the clinics carried on as before. As such for those people wondering whether to enter the president's treatment, or looking for a letter of proof in order to enter, they were put in an uncomfortable position.

All clinics had previously given a strong line to their patients about staying with their ARVs; adhering and not mixing treatments. For staff and management this was difficult, and potentially dangerous. To give any position against the president would result in severe repercussions, but for staff with long term ARV patients talking about whether 'this thing' would be better for them it was difficult to know what advice to give; balancing the health of the patient with their own safety. One staff member told me he was holding back patients who he would otherwise put forward to the eligibility committee to start treatment, "I just put the file in here [opening desk drawer]". He explained that unless he could be sure that they truly "believe" in ARV treatment they may start and then "go there" (HCW, informal discussion in clinic, August 2007). Patients repeatedly asked HCW what they should do – but they felt powerless and vulnerable in the face of the president and his media and ministry of health backing. Management of the clinics – particularly the MRC – urged their staff to stay silent, and talk to no one. If patients wanted a letter confirming their status they would have to give it. For those in the RVTH clinic the situation was much clearer; over the following months they became a de facto referral centre for those wishing to join the president.

The television coverage of the president's 'cure' of the first nine adults included coverage of one of their children – who the president repeatedly referred to as 'clear'. The second batch of patients included mothers with young children; worried by being disclosed on television, but unable not to try "for my son". Many such patients, undecided and unsure, went to HCWs for advice and guidance. However, in a general atmosphere of paranoia and distrust, many staff felt if they advised against going, and then the patient went anyway it could get back to the president and they would be in danger.

As time went on a strange silence hung over the situation; business as usual for the clinics and NGOs, but without the option of voicing any opposition to the president as he continued to broadcast his successes and more patients from across the country came forward to be 'cured'. Within even internal trainings (across the ARV programme) staff who had talked easily previously struggled with the moral dilemma of how they could discuss salient issues – treatment but no cure – in a situation where there was now a 'cure'. Within this period it was normal to discuss, informally within the clinic those they knew who had gone; whether they were ARV patients and whether those already there were ill. It also became rather than a de-pluralised biomedical environment a re-pluralised environment where patients had legitimate recourse to the president's 'cure'. For those in the groups – who knew the president's early patients well, and came to know others – they were also aware of the deaths, including some of those released as 'cured'; not publicised or admitted. They, seemingly alone, became aware that the president's 'breakthrough' was a dangerous charade. This caused friction between some on the outside, still in the groups in a precarious position both politically, having not volunteered, and economically, with little support forthcoming through NGO and government channels;

> ….we know now, it doesn't work. How can you lie like that? Stand on TV and say you are well, when you know you are not? ...they are doing it for their own gain. But how does this money help you when the next day you will be dead, maybe they will spend 50 dalasi, 100 dalasi on a cloth to wrap you in, then you will be in the ground.
>
> Support group member in conversation, August 2007

Once the president began to release 'cured' patients there was great concern about where they would go; would they come back to the groups? Or return to the clinics? This created yet greater fear and suspicion, as those who had come out could also 'report back'. For the clinics this forced discussion of what to do should such people return; how would this be interpreted if it were widely known, and would the clinics be seen to be undermining or refuting the president's claims? One clinic discussed getting any returned patients to sign a statement saying that they had returned there of their own free will; not invited or coerced by the clinic. In fact few returned, some disappeared and no one knew what happened to them. A few did return, and this was a difficult process; both for the clinics, the groups and these patients. They had publicly undermined the contract of therapy – to 'believe' in ARVs, as the following

chapter describes, standing as evidence of the president's success. The eligibility committee changed the rules; previously defaulters could not restart treatment, now they could. However, second line treatment was now necessary and made available for those who did return.

As time went on, through 2007, to the beginning of 2008 (and the end of my fieldwork) the situation remained the same; the clinics continued as before, with the president's ever expanding repertoire of treatments unquestioned continuing side-by-side. The president gradually lost interest in HIV, focusing more on his new 'cures'. Notably his cure for infertility, which I watched on television in January 2008 as he spoke with a *jinni* possessing a woman who had come to be 'cured'.

For those in the groups who had endured this difficult and painful road, of fear, worry and uncertainty, losing friends and fearing they too would be required to go the 'breakthrough', frustration and disgust sometimes came through;

> I don't want to go there [one year anniversary celebration for the 'breakthrough']. Everyone is fed off! Fed off with this thing. Even the people who are there they are fed off. More than one year, they want to come back but cannot. It's like a prison. You can't do this, do that. Even another food you can't eat. If you want to visit your family you can go, but just go and come [back]. It is a prison. They eat well, but, no, it is a prison.
> Support group member in conversation, January 2008

For the clinics there has been no resolution; the 'cure' has never been publicly questioned, and remains a second viable treatment option for people who test positive for HIV. Thus what was, through 2006, described in the first half of this chapter, becoming a world of biomedical certainties – albeit with the difficulties of translation and the complications of people's lives, had by the end of 2007 become a situation of silences, of half-truths and careful advice, looking to those who 'believe' to trust with the contract of ARV treatment.

The next chapter looks to the support societies as a space. These are specific spaces, artificial in many ways, created around the HIV+ identity of their members. An identity which, as the previous chapters describe, they take on or reject to differing

degrees in different circumstances. However, as with treatment spaces, they are constitutive of this identity, as people define themselves and are defined through membership.

7. Support group perspectives

> It is us that have this thing. So it us who know how to deal with it. The argument I have with them [NAS] is about their communication, which is very negative. When the communication is wrong people aren't getting the right messages, so they see only fear, and they won't test. If you can show them even a glimmer of hope then this is the way he will go, he will take this path toward the light… if they have a test then people have a way to go on, whether they are positive or negative.
>
> <div align="right">HIV+ man, in conversation, support group member May 2006</div>

Positive prevention – the involvement of people living with HIV in their own care and support, and also prominently in prevention and community outreach activities – is part of a package of ways of dealing with the HIV epidemic internationally[85]; a travelling set of framings for HIV-related problems and solutions into which 'PLWHA[86]' are connected, 'Global AIDS' as discussed in chapter two. People living with HIV are thus the subject of the 'Global AIDS Industry's' attentions and also agents of messages and practices for others. However, this is a very personal decision – to disclose in public – and can carry both risks and benefits for the individuals concerned.

For those people living with HIV in the Gambia who are members of the support societies there are many ways in which these 'global assemblages' (Nguyen 2005) are experienced, and ways in which they are shaped or subverted to their own needs and priorities. This chapter looks to the experiences and possibilities for people living with HIV to claim rights in these local-global encounters. It looks to the ways in which the experience of being HIV positive and supporting one another in this context is disconnected from these broader meanings and makes 'local' sense within the struggle of daily life. It also examines how this disparity of meanings and interpretation, with govermentality and connects and disconnects on so many scales

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[85] Entering 'positive prevention HIV' into google generates 435,000 results, with publications and pages from all the major international players; International Aids Alliance 2007 POSITIVE PREVENTION - HIV prevention with people living with HIV; UNAIDS 2007; UNAIDS SA http://data.unaids.org/pub/Presentation/2007/positive%20prevention_en.pdf and so on.
[86] People Living with HIV or AIDS

play out and affect the lives and livelihoods of a group of people in peri-urban Gambia.

This chapter focuses on the dramatic changes which occurred during my fieldwork in the structures of the support societies and their interactions. During the latter part of 2006 within and between the groups there was a revolution of ideals and structures. The national network – GAMNASS – and the women's national network – Mutapola - came into existence among various contestations over the questions of by whom and how this situation should be managed was fraught with difficulties and power plays between different individuals and factions. Into these already shifting sands came the president's claims to a cure (January 2007) and in the year since then the experiences of people, and their understandings of what it means to be HIV+, within the support groups were shaped by the interplay of these factors.

Here I focus on the meaning of support group membership, for those who join and take an active part in activities. As well as on the pressures which shape and are shaped by these expectations. The second section looks to the networking and partnerships of the support societies, and the opportunities and pressures these presented. The third section discusses the experiences of support group members in relation to the president's 'cure'; and the similarities and differences in the opportunities and difficulties that this brought in relation to more 'orthodox' activities that went before.

7.1. *What does it mean to be in a support society?*

As indicated in previous chapters, the HIV support groups emerged, and were constituted, through a highly mediated process. It was in the context of global AIDS funding that they first began to appear. The setting up of the first support society in 2000, Santa Yalla, was facilitated by the Medical Research Council, with specific individuals – mainly physicians – taking an active part. By the end of my fieldwork (January 2008), there were eight support groups and two national networks, one specifically for women with HIV, active in the Gambia. In line with the original set-up of the groups, the majority of members agreed to visit after referral by their doctor or counsellor to the group affiliated with the clinic they attend. Such links remained strong, and new groups have been set up linked to the ARV-treatment centres up-

country, although they still link to clinics providing other HIV-related services and referral.

The meanings and practices of group membership reveal an uneasy balance and set of tensions between needs and priorities felt by group members themselves, and the expectations of donor, NGO and government 'partners' as to what such groups operating in a world of globalised HIV funding ought to be like. This sets up a tension between personal and individual concerns, wider and societal concerns, and yet broader HIV related, or altruistic, more international, concerns.

> I expect to be able to help in fight against HIV. Although I still need to expect things like income generating activities to sustain the group…
> They are helping me to speak more and talk to new people who are coming in.
> HIV+ man, support group member, interview August 2006

The meanings of the groups from members' own perspectives are strongly shaped by Gambian daily realities of grinding poverty, as well as a social and gender context which tends to promote conformism and hierarchical interactions, responsibilities and obligations, as described in chapter five, 'domestic spaces'. For group members the welfare aspect of group membership is integral to their understanding of what a group is for. However, this understanding is not self generating, and is based upon the relationships with partner organisations, and funding streams, and the activities put forward by these partners.

The groups are formed of a wide variety of people, so that there sometimes seems to be little that ties them together – only a virus. However, at least in the urban and peri-urban areas, most of those who choose to join do so because they feel they need an alternative or additional social support network.

> I then decided to join [this group] because I felt that I had people of the same status next to me and I was happy
> HIV+ woman, Support Group Member interview August 2006

> When I was told about this I cried bitterly, and Dr. X… told me that there is a support group going, and this would really help you
> HIV+ woman, interview in support group, August 2006

Strong social bonds are formed within the group and for some, especially female members who spend days together in the centres with their children, they become a second home. There is a feeling of togetherness, and that the centres are 'safe spaces', where everyone has the same problem. Strong relationships form between members, and there has been one marriage.

> I decide to join the group so that I would have support and love.
> > HIV+ woman, interview in support group, August 2006

> I decide to join the group so that I would be at ease. I do not have support at home.
> > HIV+ woman, interview in support group, August 2006

> The groups function as a forum for discussion and sharing information, as well giving members access to trainings and workshops.

> I do get HIV/AIDS information when I get to the support groups
> > HIV+ woman, group member, interview, August 2006

There are also more altruistic and public spirited motives for group membership; and a circular relationship between the help and support that is offered and which the members themselves provide for each other.

> I join the Allah Tentou group last year to do home based care so that I would help the positive people. I am just a volunteer in the group; I do not have any responsibilities. They have helped me and I enjoy doing voluntary work. Socially I did disclose it [my status] to the group.
> > HIV+ Young Male, support group member, interview September 2006

Among those who join are a disproportionate number of immigrants to The Gambia from neighbouring countries, recent migrants to urban areas, and others who for a variety of reasons feel they receive little support in their home environment – whether or not they have disclosed their HIV status.

> Some problems that I am feeling is that I am a foreigner so sometimes I feel that I am not getting the support and care. I am getting [support and care], but the Gambia is better than my country where I come from, but the NGOs are

not… the Government are not helping as I expected. Anyway this is my feeling.

> HIV+ man, support group member interview August 2006

Those who attend regularly also know that 'if I don't come someone will call', providing a reassuring link, especially for those who live alone in rented accommodation, and also transport to the clinic if they fall ill[87].

Membership is also predominantly from poorer sections of the population; there are no middle class members, and some have felt excluded by this, not wishing to associate themselves publicly with a group that only 'low class' people attend.

Those who join and spend regular time with the groups strongly value both the social and economic support they provide. The latter includes nutritional support packages, school fees and other benefits. Indeed the provision of food is a priority for many members.

> I decided to join the support group but the group is not very strong. We need nutritional support because most of us we have lost our husbands so we really need nutritional support…
> Sometimes we get a good breakfast and sometimes we get 50 dalasi
>> HIV+ woman, interview in support group, September 2006

> I decided to come to join the group to ease my thinking and to meet new friends. I'm just a member, I'm not given any responsibility. We just come to the centre and eat and go home.
>> HIV+ woman, interview in support group, August 2006

The original groups all provided a meal every day, when funds allow and so nutritional support for people who often cannot afford to eat. Members also loan each other small amounts of money (although this can also create tension) and give gifts – the occasional chicken changes hands because 'I just wanted to give it to him'. Such

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[87] Only one of the groups had its own vehicle – Santa Yalla, the first to be established. This is something that the other groups also wanted, and saw as essential to visit sick members, and provide transport in emergencies. Public transport is crowded and unreliable in the Gambia and makes meeting attendance and so on logistically difficult, and sometimes costly. A disparity which members often raised between themselves and NGO workers attending the same meetings and trainings is in access to transport; as the NGOs provided vehicles for their staff.

gifts help people to keep each other going, and to cope with the added financial burden of unexpected family ceremonies and so on. Group members stress these factors, as well as the fact that they can share information and learn about their condition both in official meetings and more importantly from each other. These relationships are not without friction, especially where the lucrative benefits from the income streams available through partnerships with NGOs that channel GF money, are shared out. Per diems for meeting attendance and occasional overseas travel can amount to the equivalent of months' earnings. As the official structures were developed in the support groups and networks through this period many of the tensions could be seen as prominent people positioned themselves to both take the lead and also receive benefits, this same mixture of altruism and self-interest and survival.

For many people living with HIV, however, the support groups impact only minimally on their lives. Some attend meetings once a month and drop into the centre when they are passing, or on the days when they have appointments, or collect their drugs from the clinic.

> I joined the support group so that I would have company. I just joined the group 3 months back. I am very much impressed about the group activities, but language is my problem. I can only speak [one local language]. For me what I do sometimes is that I ask [another member] what is going on. I am just a member and I am not involved in any activities, I just go for meetings, after meetings I go home. This has helped me because it eases my mind whenever I go to the centre.
> HIV+ woman, from rural area, Group member, interview August 2006

Others join initially and then do not continue their involvement. For people who do not join or do not attend, this is because they feel 'no need' – they see their time better spent attending to usual household duties, or working within their family and existing social networks.

Furthermore access to the benefits of group membership has, for many, to be balanced against the real, or perceived, risks of disclosure of HIV status that go along with membership of a public group. For women especially, and particularly younger women or those from more rural or stricter families, to leave the home at all is

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difficult, and raises uncomfortable questions. Many disguise even clinic visits amongst market trading, and petty selling, so as to avoid gossip. Although long waiting times in the clinics can make this difficult. Many people do not verbally disclose or discuss their status even within the group; they just attend implying their status. This is a gradual process whereby people become more accepting of the diagnosis they have received, and what it means. Many people say that they will never be comfortable taking part in public meetings and disclosing in village sensitizations, and these activities take courage.

Towards the end of my fieldwork a prominent member died, he collapsed in the street and was taken to the hospital, but no one knew to take him to his HIV clinic. Within the groups this distressing event set off discussion about carrying membership cards; with a contact number for their clinic and a group member for emergencies, but no mention of HIV. While some suggested and discussed this as a reassuring measure and a way in which the groups could support members it was rejected by the majority who saw it as potentially disclosing; indicating the degree of fear disclosure carried.

One man, an active member with a long history of work with his group recounted to me the story of being involved in a 'sensitization' event for the armed forces. He went with trainers from NACP to the barracks to talk to the men. His role was 'to give a human face' – "so they believe this thing is real". However, he said he would never take part in an event such as this again; "they just laughed". The soldiers said he had lied in order to take money for his admission, and that he was not HIV+ at all. While this can be interpreted as the soldiers' reluctance to engage with the reality of HIV, and so their own risk, for this individual it was a very negative disclosure experience, damaging his pride.

In the Gambia many people are HIV-2+, and so have tested positive, often in pregnancy, but have never been, or are very rarely, ill. For many of these people the lived experience of being HIV+ is very different from what might be expected. As described in the previous chapter disclosure of status to immediate family has generally been a condition of access to ART in the Gambia and this has been a source of contention and controversy. Many people are terrified of disclosure given the high levels of stigma attached to the disease and the potentially devastating consequences

for people's social relationships, and this may be a reason for avoiding group membership. Certainly this is why people within the groups feel that others do not 'come forward' as they have done to be with the group.

People who test positive are often 'lost' to the clinics; they 'don't accept' their diagnosis and 'run away', as described in the previous chapter. The groups, and the social network and solidarity they provide help to keep people engaged with their diagnosis, and to come to accepting it. In group meetings many different issues are discussed. Often this is practical; around funding, projects and who will take part in up-coming events and meetings. There is also a space for people to talk about issues and share information. Discussion ranges from how families have reacted to disclosure, the pressure to (re)marry, worries about children and so on. People in this environment openly take their pills, and discuss with each other which pills they have. Although I never witnessed it, I was told (by NGO workers who knew the groups well) that some people 'swapped' pills within the groups – those taking the same medicine would give them to others who could not get to the clinic to get their supply in time.

The support groups were criticised by partners in government, clinics and NGOs, for failing to meet expectations. The stress on food provision, so important as a reason for members to attend, had, for instance, by late 2006 become a sign to outsiders of the ways in which they were dysfunctional – 'all they do is sit and eat'. The vice president of one group however, felt that the problem lay with outside agencies lack of funding for further activities, not the members themselves; "Let there be activities, or most members would come to the centre, eat, and go home". That the support groups and their activities could become the subject of such diverse opinion shows a gulf in the perceptions of those involved. Government, NGO and agency staff stressing values of professionalism, which the group management also espouse. However, each side seeing failings in the other. Certainly, the expectations raised by funders are not often followed through. Many trainings in income generation are not backed up with the credit for members to set up their own small business. Although many agencies act as intermediaries in the belief that there is not the 'capacity' – in education and skills – to absorb such funds and account for them.

For those who do become more active members, taking part in events and trainings there are still tradeoffs. One female member discussed with me the difficulties involved in the education programme she was enrolled in. She was grateful for the NGO sponsorship which allowed her to study, but also had to be careful of the time it took to attend classes and complete extra work. She earned her living through petty trading; buying and selling toiletries, making and selling other items such as soap and creams. The time she used in education meant that she had less time in which to earn, this in turn meant she had less to eat, and was not as 'strong'. She was taking ARVs, which were also 'difficult', especially when she did not have enough to eat. She explained that this was a difficult balance to maintain, despite the long term benefits she anticipated through education.

For those within NGOs and government who interact with and support the support societies, their apparent lack of a spirit of voluntarism has always been a barrier to good working relationships. Many people see the support group members, and specifically those who hold offices within the structures of the groups, as self interested; looking for free meals, per diems and an easy life and not acting for the common good. Equally, the groups are not seen to act in line with a conception of how HIV-positive people should mobilise, based on international understandings and examples of activism. They do not easily conform, in this sense, to the images in which HIV positive identity, treatment access claims and an ethical/moral order coalesce (Nguyen 2005). It is an intriguing sign of the globalisation of such expectations that institutions working in the Gambia should expect groups to act according to ideal, imagined global norms.

7.1.1. Practicing membership

For members, despite their prime focus on more immediate, localised values of group membership around sheer economic survival and social support, being part of a support society nevertheless means being drawn, to some extent, into such globalised expectations and practices. The political-economic spiral of global funding requires support groups to be included in many structures and committees; this is mandatory, no matter how it is viewed from both sides, in order to signal the legitimacy of these processes to funders within the GF framework. Equally, both internationally and in

the Gambia, while the 'sick role' associated with HIV might once be to have been wasted and weak, or associated with bad behaviour and 'playing around', there is now another role to which people also feel pressure to conform after diagnosis: to work tirelessly as an advocate and project manager, or at least to take part in meetings and income generating activities, such as making soap and tie-dye materials. Over time, and through interacting with partners and attending meetings, group members - particularly the leaders - have learnt what the international community and the GF expects of a committee, its leaders and members. They have learnt the expected procedural expertise, and to enact this effectively. The values involved are sometimes quite alien to prevailing social norms, for instance in their expectations about women representatives, gender and decision-making. They involve talk that people often find alienating, irrelevant or frustrating: for example 'yes, I went there [to a meeting] but it was just "stigma and discrimination" "stigma and discrimination"… talking about nothing'. Yet people are well aware that speaking the language of funders and intermediary NGOs is the key to having productive engagements with them. This is also, therefore, the key to the material benefits that for many were a principle reason for joining the groups. For many people, the per diems, lunches and so on associated with meetings have become their major source of income. Indeed there is one example of a support group member who was discovered, after some time (although prior to my fieldwork), to be HIV negative. He had faked it, in order to access HIV-related income, and this was widely known by other long-term members. However, social cohesion being as it is he was not expelled from the group and is now more secure than many members, working within the group and drawing a salary.

Alongside these crucial material dimensions to HIV support group membership, there are also epistemic ones. Being part of a group, to some extent, involves subscribing to dominant globalised framings of the nature of disease. Thus the GF and associated institutions constructed HIV in biomedical terms and as amenable to drug treatment through ARVs, rolled out in clinic settings. The strong links between the individual clinics and the support groups, and the referral of people to groups in the context of treatment interactions, emphasised such views of disease and treatment. This is in a broader context in which Gambian understandings of illness and therapy are pluralistic, appealing to different disease aetiologies. Yet being part of an ART regime and associated support group membership has gone along with a reinforcement of

biomedical perspectives as the exclusive frame in which HIV could legitimately be discussed and treatment sought – the 'belief' discussed in the previous chapter. In interviews in 2006, group members would sometimes speak about traditional medicine; their past transgressions, or others' use. However, all were very careful to stress that they no longer sought this kind of treatment and that they were 'with the clinic now'.

As discussed in previous chapter, counselling at all the clinics involved a strong message that mixing local treatments with ART was unacceptable. As chapters one and two – bodily and domestic spaces – outline, community beliefs at this time showed a predominant belief that HIV was a 'difficult' or 'new' illness which should be treated at the clinic. The shared experience of being in a support group in turn meant that the message of ART as the only and best way to deal with HIV was reinforced for many by not only their own but their friends experiences. Especially for those with HIV-2, who have not progressed to illness, witnessing people become progressively sicker and then recover their health provided experiential evidence not only of the power of these drugs, but also to some extent the existence of HIV.

> I know about ARVs. Those who are taking the pills tell me and the doctors also tell me. I have admired the HIV positive because they look very healthy.
> HIV+ woman, interview in support group, August 2006

Thus the patients' support groups in the Gambia have, for their members, been primarily experienced as routes to seek vital economic and social support in local conditions of extreme poverty and deprivation. While medical and NGO discourses around rights and democracy are sometimes taken on board and used, they are also rejected in favour of more comfortable family and kinship ties. These primarily local meanings have been cast as problematic by actors in the globalised policy processes around funding and treatment who expect people living with HIV to conform to particular views of globalised citizenship and governmentality. Yet at the same time, group members have (as a necessary route to access material benefits) become caught up in such dominant spirals of power-knowledge: enactors of their procedures, and bearers and performers of their notions of disease and therapy.

7.2. 'PLs' rights, responsibility and representation

The following section draws upon events to illustrate, as with chapter one, the degree of interaction between the groups and the 'global'. Through these partnerships it is possible to trace the linkages; in specific events and practices, and in the use of language.

During the AU Summit held in the Gambia in July 2006, Nane Annan, Kofi Annan's wife, visited Santa Yalla Support Society (on Sunday 2nd July)[88]. Visiting the group, and taking part in the preparations in the weeks running up to this important and high profile event illustrated some of the tensions around the roles support societies should be playing, and the picture that should be given to (for example) visiting dignitaries. Prior to this point this group had been connected to the UN system, receiving financial support from the UNDP and (more importantly) having a UN volunteer placed with them for more than 10 years. However, by the time that the UN Secretary General's wife wanted to visit a project in the country, this volunteer had moved on, although was still in the country, and there were no active projects running with any UN agency.

The funding of staff and running costs as well as projects and activities was "complicated, as different programmes are funded through different channels" (support group worker, non-member (HIV-) member of staff, paid by CRS, 20th June 2006). At this time staff and running costs were covered in part by many different agencies – GF, HARRP, CCF, US Ambassadors' Fund, ActionAid[89] - however, there was a great deal of insecurity over who would continue to pay, particularly for staff costs which had been covered in the last month by the US Ambassador's fund, but as a one off. This was in the period where the HARRP project was scaling down, prior to its closure at the end of the year, and already the insecurities were plain.

Within the group there was a great deal of excitement and pride, as well as expectation – it is customary (within the Gambia) for high-profile people to make a donation when they visit. Nane Annan would be accompanied by various other

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[88] http://www.un.org/News/Press/docs/2006/sgt2497.doc.htm
[89] Those listed by manager during this conversation

Gambian dignitaries so there would be a group of people to make donations. The centre was cleaned and new lino laid throughout. The kitchen – cooking pots, bowls and wood burning stoves – were moved from the front veranda, where they were used everyday – to the outside space behind the centre. In one of the back rooms tables were put out as stalls with the produce of the groups IGA activities: tie and dye materials and clothes, soaps, jewellery one member had brought back from Senegal to sell. Usually this room was bare but for some foam mattresses where members would sometimes sleep during the day. There was a great deal of expectation that these people would come with money and should buy.

The cleaning and preparation was taken on enthusiastically by some members, and actively avoided by others. Preparations were observed by various outsiders who came and went, some of whom expressed a fear that the event would be "an embarrassment", due to the lack of effort by members, and also the different standards of cleanliness and organisation they perceived were necessary, and that they saw the group failing to achieve or even appreciate. No one felt it would be appropriate for Mrs Annan to visit the centre as it was, or see what people usually did there.

In the event the visit went very well, speeches were given by different people – both dignitaries and members - Nane Annan inspected the wares on display (although, disappointingly, did not stop to shop) and was whisked away. In line with the general experience of meetings and events in the Gambia this event had been planned for the Saturday, however Mrs Annan's prior appointment over-ran, and so Santa Yalla were postponed to the following day, they went home, and returned the next day and performed as required. It was not possible to tell if the visitors gave generously, the centre staff were quiet when asked about this afterwards.

Both the president and a prominent female member gave speeches, in English, outlining the experiences they had had, in testing and in coming to the group. The female member spoke movingly about the positive effect coming to the centre had on her life when she was in despair; stressing that to come there and find other 'well dressed' women made her feel more confident and less ashamed.

After the dignitaries left there was food, music and dancing – the UN had provided some budget for the event; for the decoration of the centre, and for transport fees and per diems for members and provision for everyone to eat. The general mood was one of having had a good day, meeting someone who encouraged them and was important and interested in their centre and their lives. Particularly for the members having told their stories on stage, and discussed the importance of the centre. For those outside the group the main emotion was relief.

In this case several important issues are played out between the lines. Although the focus was on 'getting it right on the day' it exposed ongoing tensions behind the scenes in terms of expectations on both sides for behaviour, performance and financial support; for rights, responsibilities and representation.

7.2.1. NGO-speak – "we PLs…"

HIV, as described in earlier chapters, is a field of rich metaphor and meanings, thus the language used to discuss HIV is important. The world of international HIV programming is thick with language and meanings. UNAIDS regularly issues 'Terminology Guidelines';

> This list of UNAIDS' preferred terminology has been developed for use by staff members, colleagues in the Programme's ten cosponsoring organizations, and other partners working in the global response to HIV. Language shapes beliefs and may influence behaviours. Considered use of appropriate language has the power to strengthen the response. UNAIDS is pleased to make this list of preferred terminology freely available. It is a living, evolving document reviewed regularly.[90]

The importance of language is undeniable, and the effects it has on the priorities and programming of different agencies, from funders to implementers to beneficiaries also illustrates the power of global discourses.

> Most ideologies are religious or political, but we also stumble over the politically correct convictions of AIDS activists who led the initial charge

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[90] Quote from publications list detailing the 2008 version; http://www.unaids.org/en/KnowledgeCentre/Resources/Publications/; available online http://data.unaids.org/pub/Manual/2008/20080226_unaids_terminology_guide_en.pdf previous versions can also be accessed through the UNAIDS website

against HIV. Whatever their source, these ideologies influence what we do about sex and drugs and determine how we do it. Money, of course, follows the dominant ideologies. But it also sucks in people who don't really care about the problem, who are truly queasy about sex and drugs, but who want some of the cash. When AIDS was unfashionable, we had thought more money would make it easier to do the right things to prevent a wider epidemic. Now that it is a boom industry, it has become clear that money can actually be an obstacle to doing the right thing.

<div align="right">Pisani 2008; 11</div>

What is also important is the way in which language trickles down to those it is meant to describe and is taken on. From the first meetings I had with support societies in the Gambia I was surprised to hear people refer to themselves as 'PLs' – in meetings among themselves, with others and in general conversation. PLWHA – People Living with HIV or AIDS – is the accepted acronym around the world, and here it becomes not a useful textual device to save the fingers, but the label that these very people apply to themselves. As Cornwall discusses;

> Words make worlds. The language of development defines worlds-in-the-making, animating and justifying intervention in currently existing worlds with fulsome promises of the possible.

<div align="right">Cornwall 2007; 471</div>

However, whose words are these – and which worlds do they make possible? Within this there are many meanings, from my conversations with 'PLs' this term denotes a sense of solidarity with a mutable concept of people living with HIV internationally, and with the activities and campaigns that exist out there. However, the information available to people living with HIV is often patchy or incomplete. On different occasions prominent group members – more linked into a sense of the international – spoke to me about the quality of the drugs they received. The general perception was that 'we' – in the Gambia or in Africa – do not receive the same quality of drugs as those in Europe or America. People were aware of an international campaign for access to ARVs and identified with it in a vague way, even though it was largely irrelevant to them; receiving free medication through the GF programme.

Many other terms – notably 'stigma and discrimination' and the ubiquitous 'partners' were dropped into discussion in English. Such words and phrases come directly from

those very partners, direct from GF and other international agencies and funders, in many cases divorced from the reality as experienced. Translating 'stigma' proved very difficult, and prompted discussions of 'sitting alone' and 'eating alone' both terrible fates. Many people had examples of people who had died from 'sitting alone' – as the nurses described in the last chapter – it is this isolation and the despair it caused in such a vitally connected community that kills, rather than any disease. However vital people judged this to be the repetition of 'stigma-and-discrimination' in meetings and other settings was somehow removed from the more keenly felt Gambian sense of isolation that can kill. However, the repeated use of such phrases illustrates the extent to which 'NGO speak' is taken on and employed, signifying a sense of connectedness to international concern and campaigns for the issues as expressed in this way.

7.2.2. Networking

As the national networks came together in 2006 there was much discussion as to how this would relate to the existing groups. As the main national network – GAMNASS[91] - were to supersede the existing groups, acting as an umbrella organisation, this would change the power dynamics, and the routes through which partnerships were formed and benefits distributed. The process was supported by different partners, a national network being something which 'should' exist, and could streamline the negotiation of such relationships. For many this process was flawed; controlled by certain actors and marginalising others. For those who were in positions within the existing and well-established groups this was a challenge to their ability to form partnerships themselves and to attempt to steer funding initiatives. The women's national network similarly set up a tension between the groups and a new organisation, but also a tension within the groups, where only some members were to be represented. The women's network in particular faced allegations in the beginning (from both men and women who felt sidelined) that it was not a national network, but represented women from only one group.

The women's national network – Mutapola – is supported in particular by ActionAid The Gambia (AATG). It is based on a pattern which has been implemented elsewhere,

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[91] GAMbian Network of AIDS Support Societies

and the name in fact comes from the South African, and initial, project[92]. The concept of networks for people living with HIV, as well as support societies, is facilitated in the Gambia and based on experiences in other contexts. How much the differing political and social contexts are taken into account by the implementing partners is highly variable – some partner organisations attempting to facilitate a member-led and more organic process. However, linked into the expectations of parent organisations, or the experiences of other country programmes tensions arise where the members are unaware of what they are expected to do, or if their (mainly welfare based, rather than advocacy or education based) expectations differ from those implied within project outlines. Although it is necessary to stress that partner organisations include funding for nutrition programmes and IGA, and group members want to take part in education programmes and advocacy campaigns (such as the candlelight walk and World AIDS Day celebrations). The tension lies in the prioritising of events and the attitudes of trust and suspicion which circle around often thwarted aims and expectations.

Organisations, and often the key programme managers as individuals, take on the traditional 'patron' role which is major structural component of all relationships in the Gambia. This is true of health staff, often counsellors and social workers who take a lead in the clinics' relationships with groups, as well as NGO and other organisations' staff. Many of these individuals will talk about not only 'their' project, but 'their' group. Even though a particular group of members (beneficiaries) may overlap with others, and may receive funding from different organisations for different (although perhaps too similar) projects. This has caused problems and misunderstandings as the groups look to maximise the support they receive and partner organisations wish either to prevent duplication of projects with others, or even to somehow ring fence 'their' group and so guarantee the legitimacy conferred by reaching their target beneficiaries, and justify their funding.

Through these various negotiations and partnerships what exists as 'Global AIDS' – sets of meanings and practices which form the global 'fight' against HIV and AIDS – appear in the lives of those people living with the virus in the Gambia. However, these programmes, meanings and language codes, often well planned and

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[92] http://www.comminit.com/en/node/130960; http://www.actionaid.org/main.aspx?PageID=834

implemented, do not transplant as well as might be expected to this context. In the last few years the Global AIDS industry has moved away from a one-size-fits-all need to implement and 'roll-out' 'best practice' around the globe. However, the impetus to bring what 'works' to countries such as the Gambia, and speed the support groups along a well-worn path takes little account of the daily realities of these particular people. Also, more importantly, it does not take account the political and social institutions and patterns, and the lack of any history of political activism, or the lack of any need (with drug provision patchy but in place for free) for activism on global issues such as this. In fact the main aim of networking – to link into regional and international networks – is an aim which highlights this more clearly than any other. The financial gains for Gambians travelling to international meetings can equal years of wages in dollars for a few days. While the opportunities to meet with and learn from 'PLs' in other contexts is valued, the financial security such an opportunity brings is just as important. Partner organisations try to slide past this uncomfortable truth without addressing it head on, while group management structures and relationships between members strain under the weight of choosing who should benefit.

At the end of 2006 after months of negotiations, GAMNASS had an elected national committee, and work plans were drawn up. A constitution was drawn up and agreed upon, through a painstaking process of translation into various local languages and discussion over several days. As an organisation it seemed to be moving in the right direction, although rife with individual competition and rivalries. Accusations of self-interest were common, and although the elections were satisfactory to most there were whisperings in some quarters about what the network would really do for them. One woman who was elected to hold a position in GAMNASS was questioned by other members of her group; "do you go from home to that place, or do you go there from here?" Asking her to make plain her allegiance; whether she sat as an individual in that position, or as their representative. Arguments such as this were common as people tried to work out this new institutional landscape and work out how it would work.

During this time gains were made, as the various roles were fleshed out. In conversation with the then president of GAMNASS in September 2006 our discussion

spanned many different topics; achieving 'parity' between the groups, the difficulty of obtaining funding from partners (he had the idea that bringing all partners together to hear what GAMNASS proposed to do might spur them into dividing the proposed activities between them); 'bringing people out' to join the groups and so receive the 'benefits' of membership; and the new policy of including people living with HIV as counsellors . This had been agreed in principle and taken up in two of the clinics[93].

Thus in looking at the hopes and expectations, as well as the frustrations of the nascent networks in the Gambia, it is possible to see the ways in which opportunities are interpreted and negotiated for by people living with HIV. Here exploring the experiences and practices we find resonances with these arguments about emergent therapeutic citizenships (Nguyen 2005; Rose and Novas 2005).

7.3. *Experiences and reflections on the president's 'cure'*

In The Gambia, as elsewhere in the region, the 'big man' is all important, and people's links of patronage and to those in positions of power or influence importantly shape their social standing and economic welfare. The president is the biggest of the big men and those living with HIV, among the most vulnerable. President Jammeh has in the past often shown his support to people living with HIV, for instance in donating money or large quantities of rice and oil for Ramadan which is shared out among group members. And so, when the president called for volunteers for a treatment programme, people who had received such gifts before felt it their duty to attend. In attending, they had little real indication of what they would be subjected to. Many probably expected more of the same: some rice, some oil, perhaps some money, and of course expressions of gratitude to the benevolent leader. Most of the early volunteers probably expected to return to their homes that same day. Yet months later, most were still confined in Serrekunda hospital undergoing the president's treatment.

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[93] Hands on Care in Brikama had previously had a policy of having 'peer counsellors' and reintroduced it around this time; RVTH took on two counsellors, one male one female who worked as closely with the existing counselling team. This was a new development for them, but one which they took to enthusiastically. MRC never introduced any kind of peer counselling in their GUM clinic. A major advantage was seen in counsellors being able to say 'I have this thing', and particularly for the women in PPTCT; that they could talk to someone who had been through the process.

When the president first announced his cure, there was much confusion for those people in the support societies who were not in the initial group of nine patients. On the one hand, they saw offered what they had hoped and wished for - a cure for AIDS. This contrasted with what they had always been told about ART - that it could hold back AIDS, but not cure it. As discussed in the previous chapter, a constant challenge to the staff of ARV treatment programmes is the difficulty of separating 'treatment' and 'cure' in local languages – the concept of a treatment that does not actually get rid of the sickness is thus hard to grasp. Health centre staff struggled to give metaphors which could convey this without allowing people to feel that ARV treatment is 'useless' or 'failed'. The president throughout his early speeches and statements, speaking in English, however, had a clarity and claim to real cure that the health centers cannot compete with: 'Within three days the person should be tested again and I can tell you that he/she will be negative'.

On the other hand, group members also saw their friends paraded daily on television, naked and vomiting, crying, with their dignity and sense of cultural propriety in tatters, but always maintaining their faith and thanks for the president's intervention. It was such scenes that led some people in the groups to become vocal opponents – in private – of the president's treatment. They said 'it was the television that saved us', freely admitting that but for the way in which they saw their friends exposed they too would have joined. After the first nine patients were shown publicly, disclosed and exposed naked on television without their consent, those left behind met to discuss their outrage. At this meeting, with the leadership absent with the president, new voices started to come through. All the groups agreed that they would not answer further calls for patients, and the general feeling was that 'if we don't go, no one will'. The groups considered themselves to be the most 'out' people living with HIV, those prepared to disclose to each other, take part in public events and so on. Those who they considered to be unwilling to make this step, they felt, certainly would not want to be shown on television.

Yet as it turned out, the first two groups of volunteers were almost all from the support groups. A mix of hope and fear led them to volunteer. People felt that 'he [Jammeh] would know' and feared retribution for not complying when he called. By this time the small son of one of the original patients had been declared 'clear' over

and over again on television by the president. Many in the second group were women with young children who felt that they had to try. If this was the only chance to have their child 'clear' too, then they had to take it, no matter the cost to themselves. Thus it was that the mixture of hope and fear which the president's treatment creates, and which every person given an HIV+ diagnosis lives with, led people to volunteer in large numbers. They took a leap of faith - but in many ways no more a leap of faith than ART, and potentially with more concrete results.

At this time, most of the discussion within the groups turned on questions of disclosure and exposure, and the conditions experienced by people on the treatment programme, rather than on the efficacy of the treatment itself. Gradually however people did come to question it, but within a dynamic that remained within the safe confines of the group as people shared their own views and reflected on what they had heard from health staff and NGO workers. People's discussions did not come down clearly on one side or the other. For example, I sat with one of the groups on the day the newspaper headline ran 'Proof of Cure', publishing CD4 counts and viral loads, and discussed what this meant, and whether this was in fact proof of anything. Some people were moved very quickly to discuss the value of traditional medicine, while some also reflected that maybe the treatment was 'the same as ARVs'. Very few people were quick to rule out the efficacy of the president's treatment.

As time went on the third, fourth and fifth groups volunteered and entered treatment. These were, contrary to the groups' expectations, people they do not know. People from all over the country have voluntarily registered, after seeing the 'success' on television. People in the fourth group which entered in early August 2007 included foreigners from neighbouring countries who saw the cure on the internet and came to take part. The president's recruitment has been far more successful than the GF's ever was.

As so-called 'cured' patients started to fall ill and die, however, people in the patients' support groups came to question the presidential treatment further. Most, by late 2007, were clear that they would not volunteer. Many group members came to consider the president's cure as a charade, and themselves as amongst the few people in the Gambia to be aware of this. While they attend funerals for deceased friends,

others, who are still with the president, continue to speak on television about their regained health, and give thanks for his care. Some of the names listed in the newspaper as those who went home 'clear' of HIV were very sick, while others had already died - or did so soon after being reported 'cured'.

The pressure felt by those inside the treatment programme was intense, certainly there was no room to criticise the president, or express doubts. The potential benefits of showing active support and testifying to the success also put immense pressure on people both fearful and confused by the events unfolding around them.

The epistemic framing of discussions around HIV within the groups also shifted. Whereas before, discourse within the groups framed HIV exclusively as a biomedical disease, in the light of the president's 'breakthrough' these have become forums where people discuss the relative merits of ART and herbal treatment in a way which was never possible before. Several group members who had been in the background, now came to the fore, and are seeing the benefits of forging links with NGOs and taking over leadership roles – while in the parallel treatment regime others took leadership roles and positions linking themselves strongly with the president.

Within the presidential hospital, tensions and politics between people being treated quickly took hold. Existing tensions between leaderships of different groups who had been in competition for NGO partners' attention within the GF regime continued inside the president's regime, and soon evolved into competition to have roles within this new environment. One patient became the coordinator; others wore white coats and took over responsibility for massaging the herbal remedy into their fellow patients. Gifts of money and 'salaries' were given out by the president. Distrust and argument grew. Several patients were reported to the president for various infractions, and reprimanded during the evening sessions at the statehouse where treatment took place. In this environment some became sceptical, and others were expelled from treatment.

In some respects, then, the patterns and practices evident in the context of the GF regime, before the presidential 'breakthrough', were replicated in the latter. In participating in both, there is a sense in which support group members 'play the game'

in order to access the benefits of association, be these economic, social or in access to treatment. Just as in the GF context there were tensions as we have seen between the ways in which authority structures imposed values and expectations in return for such benefits, and became disappointed when their particular expectations of participation, representation and so on were not met, so similar patterns were repeated within the presidential programme - even though the authority structures, resting on Muslim, traditional and Africanist foundations, are so different.

It is not surprising that people learn to speak the language of clinics and NGOs - or of tradition and presidential power - in order to access the best care and advantages they can. This is not to say that people do not come to take on board such positions; in context, they speak and feel strongly the logic and sense of the positions they are adopting, whether these be based around ARTs or traditional medicine - becoming in effect subjects of these particular forms of governmentality. However, with the authority structures are in such conflict the landscape became both a difficult and confusing one to navigate, especially when people were playing for such high stakes as their livelihoods, their health and their lives.

7.3.1. Personal testimonies as evidence

> I want to thank every Gambian, the patients, especially, the first batch that is the lead for the trust.
>
> President's speech on the discharge of 13 cured patients[94]

When the original nine adults entered the president's programme, they were immediately called on to stand up in public – nightly on television – as evidence of the programme, its workings and its foundations. Shown in the role of benevolent, mysterious healer and devout Muslim, the president personally and publicly administered his 'cure' to these people. They were displayed drinking the concoction, and attempting with varying degrees of success to hold it down. More shocking to many viewers than this, they were all – including the women - shown wrapped in towels, naked from the waist up, to receive the healing power of the leader's touch in herbal massage. Here, both the president, resplendent in his signature voluminous white robes, and the patients, vomiting and shell-shocked, with little dignity and less

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[94] Sunday, June 17 2007, www.statehouse.com, Accessed June 2007.

power to choose their roles, stood in effect as human testament to his cure and his personal care for his subjects - even though he chose to protect himself with plastic gloves from actually touching them[95].

Throughout the progression of the president's programme as more and more people volunteered for treatment, he and his supporters stressed the need for openness, emphasising that all should be prepared to be shown on television. In fact only the original nine bore the brunt of such intense media scrutiny. Furthermore, this requirement was waived for 'important' people. Stories have long circulated in The Gambia of members of the elite, Imams, Doctors and wealthy professionals who are HIV-positive but who refuse to disclose, and, being better off, have no need to. Some of these people did come forward for the president's treatment, but were not shown publicly out of sensitivity for their position; thus power and privilege enabled some to avoid exposure that Jammeh had originally constructed as necessary for the treatment to work.[96]

At the beginning of 2007 the media coverage was intense. Every night the patients were shown for several hours on GRTS, the single national television channel. For the many Gambians who had heard of HIV through community education but barely considered it, this became a kind of soap opera, and one which tended not to work to the benefit of those displayed: 'I know that one! She sells milk in the market; I won't buy milk from her!' As time went by the footage was repeated, so the same women were shown vomiting and crying on different evenings. The patients were also called upon to express thanks. Some took to this more readily than others, testifying to the 'miracle' of their regained health and strength. Some also joined the president in his condemnation of 'western' medicine in comparison to the miraculous 'breakthrough'.

Treatment testimonies are also stock-in-trade of the mainstream biomedical AIDS response. In South Africa, for instance, treatment organisations have sought support for ART by encouraging others to witness the transformations 'from near death to

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[95] Apart from the television coverage, images showing the treatment are also shown on the president's website; www.statehouse.com

[96] President Jammeh announces to participate in the treatment of hiv/aids and asthma, 18th January 2007, http://www.statehouse.gm/pres-rvth-board_170107.htm

new life' of ARV patients (Robins 2005). When the president calls on his patients to talk about their 'miraculous' return to health, and to come out and stand in public, he is mimicking a well-rehearsed call of the 'orthodox' HIV movement.

Jammeh and his supporters have used further strategies to strengthen the apparent power of such testimonials. For instance, both television and newspaper reports stated that the first recruits were frail and sick, unable to walk even short distances, giving weight to the president's claims of a miraculous recovery. However, knowing the people involved, these claims were vastly exaggerated . While for many, living under the president's care did bring definite benefits in a much improved diet, some - through living in close confines - became more ill than before, succumbing to malaria or TB spread from the several patients who were dual infected with HIV and TB.

Throughout the programme, Jammeh has also made comparisons with ART in its effects on patients to 'prove' its effectiveness. This underlay his decision to take people off their ARV medication when they registered for his treatment:

> Indeed without doubt, President Jammeh is the first person in the world who has found the treatment for HIV/AIDS, through traditional medicine and the gift of Allah. The proof of the effectiveness of President Jammeh's treatment is that although it was claimed by some critics that the patients who were under AVR will die if they stop taking such medications, these have proven critics wrong when President Jammeh asked those patients on ARV to stop taking them. This proved that, the claim of the critics are unfounded and the patients who have abandoned ARV and continued President Jammeh's treatment have survived and are cleansed of the desease…. Indeed, if President Jammeh's medication is false, these patients would have die by now. Today they are alive and are living proofs that President Jammeh can get rid of and will get rid of HIV/AIDS.[97]

The sight of people claiming to be restored to health, standing on television and joking with their president, seems to have been an important factor in convincing others to come forward. For example:

> One of the foreign patients, said when she was first diagnosed with the desease [sic],she felt very sad and discouraged in life, as scientists

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[97] *Daily Observer* ,October 24th 2007

believed that there is no cure for the desease. She said, "one day I was watching the television in Rabat, Morocco, when I saw President Jammeh treating people with HIV/AIDs and I said I must come to The Gambia for the treatment… This is why I am here. However, since I started the treatment, my condition has changed. I will call on all and sundry to come for the treatment". [98]

In the Gambia many people are not literate, and the television and radio are their main source of news, aside of course from that passed from person to person. Oral testimony appeals both to an oral culture and its valuation of oral history and news transmitted by word of mouth, and to a particular sense of truth in 'frontstage' public discourse. Thus it is the gravest of insults to call a Gambian a liar, even when 'backstage' realities and discussion suggest a different version of events (see, for example, Ferme 2002 and Murphy 1998, for examples from across Mende speaking West Africa). In this context, in speaking out, the people involved provided visible and irrefutable proof – when they themselves publicly claim to have been restored to health who can say they are lying?

At the same time, treatment testimonies can also interpreted as shows of loyalty and affiliation to the president. Jammeh has in the past given significant patronage to people living with HIV, for instance in the form of gifts of food and money to support societies. In a further mimicry of mainstream biomedical AIDS treatment, Jammeh and his supporters constructed participation in his programme as a route to receipt of patronage resources and closeness to power.

By 2008 Jammeh had tightened the rules and regulations around his programme, both in response to internal wrangling among patients, and to what he described as 'attacks' from outside. As newspaper reports described:

> The Gambian leader told the patients that "even if you are with your wife for the first month or two, you will not do sex, no alcohol, no smoking or eating of pork. All these things are not allowed during the treatment. He also warned the patients that they are forbiden [sic] from taking anything outside, be it food, drinks, medicine, fruits, among others, adding that if he detects anybody taking things outside the treatment, that particular patient

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[98] '32 start HIV/AIDS treatment' *Daily Observer*, August 13th, 2007

will be asked to leave. He said the reason is very simple "as there are people outside who may try to give you retroviral drugs or other things to sabotage the treatment as they may have something against this treatment.", noting that even a cup of tea will not be accepted.

President Jammeh further stated that visitors will not be allowed during the course of the treatment. "If you are found with the visitor, you will go home with him. They can send even your relatives because they have something against my treatment and if they give you anything, if you take it and later die, they will say it is the President's medicines that killed him or her. Even your wife or husband is not allow to visit you or bring you anything. You will not also go to your homes for the first one month and you will not visit your family members. The white people can do anything to sabotage the treatment"[99]

Thus the people in his programme - the president's 'proof' – were forcibly protected from tampering by outsiders looking to 'sabotage' the experiment.

Given the longstanding power of testimonials in relation to mainstream HIV care, and given prevailing oral cultures in The Gambia, 'believing' in people-as-proof in this context is therefore neither new nor irrational. Like the use of numbers, described in chapter two, this is another kind of evidence that President Jammeh has taken from one context, and re-presented within the framing of his own treatment regime.

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[99] '32 Start HIV/AIDS Treatment' [fourth group of patients], Daily Observer, August 13th 2007

8.   Conclusions

8.1.   *Summary of research and findings*

Globally the 'fight' against HIV and AIDS has many elements. One important, and costly, aspect is ARV treatment. As a clinical intervention ARV treatment is currently the only recognised effective treatment for HIV and AIDS. Among the many hopes around HIV treatment is that for those living with HIV this will become a chronic and manageable condition, and so the stigma around HIV reduced. However, this is dependent upon the ways these individuals manage their illness, both as patients and in relation to treatment(s), but also as people in relation to their families and networks, and the process of disclosures within the different spaces of their lives. This research has explored and illustrated the ways and degrees to which this is possible and the ways in which it is constrained in the particular context of peri-urban Gambia 2006-2008. This focus on a relatively low prevalence country gives an insight into how meanings and understandings are created around HIV. Here not only the lack of an 'emergency' level of infection, as well as the local-global linkages of very different kinds link to shape particular ideas about HIV and its treatment. In this final chapter I first give a summary of my research findings, organised around two key themes which emerged from my research. The second section addresses some key debates around HIV treatment, and how this research speaks to each of these.

ARV triple therapy is the most effective treatment for HIV infection and, despite concerns before international provision was initiated, cost-effective (Creese et al. 2002). Recent research also points to the effectiveness of earlier initiation of ARV treatment in curbing transmission (Donnell et al. 2010; Dabis et al 2010; UNAIDS 2010). Despite this in light of the global recession there are fears around the continued funding of HIV programmes, even treatment (Revill et al 2009). Thus at this time it is vital to consider the ways in which people take this treatment, and integrate it into their lives, if the current roll-out is potentially to be expanded as a prevention measure.

While there is a growing literature focusing on the social context and practice of ARV treatment, this research fits within this, adding a further comparative example. Further

attention to the lives of people living with HIV, and particularly members of support societies, is also necessary in light of discussion around decentralisation of health services, for instance, home based care workers and lay counsellors, as have been utilised to some extent in the Gambia (Boyd and Nwizu 2010; Sanne et al 2010; Macgregor 2010).

Such decentralisation is also part of UNAIDS vision for "treatment 2.0". This report envisions the possibility of a one-third reduction in HIV infections, based on five pillars: creating a better pill and diagnostics; using treatment as prevention; stopping cost being an option; improving uptake of HIV testing and linkage to care; and strengthening community mobilisation (UNAIDS 2010; 1). Within each of these aspects there is a need to consider the perspectives of the people at whom such interventions are targeted, as well as the ways in which the interventions already in place are functioning and being negotiated and re-shaped by these actors. This thesis has addressed these questions.

HIV treatment is not only a clinical intervention. It is part of a web of interventions which link treatment, prevention and care, these in turn linked into international chains of funding and thinking. As chapter three has demonstrated, these global spaces manifest themselves in various ways in the Gambia. As this research has shown through each subsequent chapter, being HIV+ and taking treatment links people into relationships with clinics, NGOs and (through the NAS) the GF. These links operate to form the ways in which people see their own condition, and their choices. They also open up potentially lucrative income streams and opportunities.

As ARV treatment is rolled out internationally it is increasingly important to look to how these drugs are experienced by those taking treatment. Such concerns link this study into a growing literature on the dynamics of HIV treatment internationally (see for example Nguyen 2003; 2005; Booth 2004; Hardon et al 2007; Schumaker and Bond 2008; Alcano 2009; Meinert et al 2009 Kalofonos 2010; Richey 2008; 2011a; 2011b; Seeley and Russel 2010; Watermeyer 2011). As elsewhere in these studies, this thesis has looked to the social side of ARV provision: the daily experiences of people living with HIV in the Gambia; those taking ARVs, and others, particularly members of support groups for people living with HIV.

Internationally people living with HIV have become experts, in their own treatment and in campaigning for their rights both to medicines and to other forms of support (Epstein 1996; Robins 2005). This literature points to different processes of legitimation and expertification. How does this play out in the Gambia? Are the members of support groups becoming 'experts' and active patients? Is this a phenomenon which can be seen in this setting? For example in Uganda Russell and Seeley (2009) point to the role of livelihoods in this process of moving through trauma and distress of diagnosis towards 'normality', and to a "narrative of work" being an effective part of this transformation. While links to support group activities, and a reliance on the income that some gain through these links, indicates that an ethos of work is important to people living with HIV in the Gambia, the fact that for many their work is done voluntarily curtails the reformation of such an active HIV+ identity. This is particularly the case as many judge their own rewards for work against the staff of NAS and NGOs, who receive regular salaries and other benefits through working in HIV, which are denied to those working within the support societies.

The most obvious example of 'expertification' in the Gambia is that of the president, and his 'breakthrough'. In tracking the progress of the president's 'cure' and his patients as they went in and came out of his programme it is possible to see, as I described in chapters four and six in particular, the ways in which the president shored up his own 'expert' status in both opposition to the established 'Western' biomedical establishment, and in relation to it. Here people living with HIV were drawn into a seeming battle between two systems in conflict. Here, then, both of these systems effectively co-opted the people which they treat, asking for 'faith', as discussed in chapter six, in relation to either treatment. The broader political and economic realities of this clash prevent a more meaningful engagement. As such the degree to which people as patients were able to exert agency and make real choices was severely constrained. Instead their roles were to stand as evidence – their blood, and the readings taken from it, and their testimony standing to reinforce the expert status of the president and the 'success' of his 'cure'.

This research set out to explore how the ARV treatment programme was experienced, how the availability of treatment impacted on people's experience of being HIV+ and how the availability of treatment also changed perceptions of what it means to be HIV+, both individually and at a societal level. While the study was always set within the plural health context of the Gambia, described in detail in chapter four, it also became a study of the president's 'breakthrough', as this was positioned as a viable alternative to mainstream clinic-based treatment.

The core questions that originally informed this study were answered in several ways, as the following sections elaborate. Firstly, a focus on 'spaces' - which emerged as important through my experience of fieldwork - has been represented through the organisation of the chapters of this thesis. This changeable and contextual reinterpretation of understandings of what is means to be HIV+ in different environments, by the people living with the virus, shows that there is no one interpretation, even for each individual. Through tracking the ways in which people navigate different spaces and disclose and strategize differently within them a more nuanced picture of the experience of being HIV+ and taking treatment has been possible.

Secondly, the changing ways in which treatment itself was imagined became important to this study. This ethnographic research took place in the Gambia during 2006-2008. As a low prevalence country embarking on ARV roll-out many issues and challenges were faced. Not least among these was the general lack of awareness of HIV, where most people would say that they did not know anyone who was positive. With the emergence of the presidential 'cure', in January 2007, this reality was challenged: with the president and his patients appearing nightly on television no one could say that they had not heard of HIV, or seen someone who had it. This chain of events also fundamentally challenged the growing ARV treatment programme, and the biomedical basis of interventions around it. Thus a process or project of de-pluralisation, evident at the beginning of my fieldwork, was replaced by what I have termed a re-pluralisation of HIV treatment. The solidification of ideas about HIV being 'for the clinic' – the predominant view from interviews in 2006 – was replaced by a re-pluralised system in which the legitimacy of such interventions were effectively challenged by the president with the machinery of the state and ministry of

health as well as the national media in public support. While such processes can never be complete, here, within certain spaces (particularly clinics and associated support societies) an appearance of de-pluralisation had been achieved prior to the president's 'cure' announcement. Of course, the same people who enacted this de-pluralisation within such spaces, both people living with the virus as well as health workers and others, may have engaged with alternatives in other spaces. Similarly some of these same people enacted a dramatic 're-pluralisation' as previous chapters have described.

The theoretical frame I have chosen for this research also allowed some space to look to the link between structure and agency. This is linked to questions of how people are able to engage with issues or are co-opted, and make strategic choices and judgements which can have serious consequences for their health and well-being, and their livelihoods. HIV and AIDS have always been sites of contention, with activists and experts defining and redefining both the science and the politics (Sobnosky and Houser 1999; Epstein 1996; Robins 2008; Richey 2008). However, as with the discussion of the president's intervention, the lines between who can be considered an expert are often blurred, particularly in such medically plural contexts as the Gambia (Fassin 2008; Fassin and Fassin 1986). Here I summarise the key findings of the thesis in relation to these two areas – 'spaces and agency' and 'knowledge and biomedicine'.

8.1.1. Spaces and agency

This thesis has been structured around the 'spaces' through which people move; the spaces where their experiences are shaped by structures and expectations, and which they shape themselves through their attitudes and agency. For any given person their experiences and understandings of being HIV+ and their comfort or discomfort within these spaces is variable; within and between spaces at any given time and as a process over time.

Thus in clinical spaces and support groups a more global sense of an HIV+ identity is created and recreated daily. In the clinical space these experiences are explicitly biomedical with a focus on treatment as well as on the monitoring of numbers and measures of health or ill-health. Within the spaces of HIV treatment support groups such experiences are reinforced, and also fit into a broader context of programmes and

projects which reinforce the values of adherence, of public disclosure, of fighting stigma, and of ideas around 'rights and responsibilities' for people living with HIV. Such transfers of language and ideology form a strong web of connections from the local to the global, the global assemblage. However, I often found that such information could arrive in the support groups in the Gambia incomplete, or be reinterpreted in quite interesting ways, thus more reminiscent of "the point-to-point connectivity and enclaves which confront us when we examine Africa's experience of globalisation" (Ferguson 2006; 47). Thus for example, in chapter five we saw how people take on and reinterpret advice around their behaviour, in particular related to reproduction and marriage, in the context of local values and norms. Similarly in chapter seven, the ways in which people in the support groups interpreted their relationships with NGO and government workers were not always as intended according to international norms and plans, as is also described in chapter three.

Within domestic spaces struggles to maintain privacy come to the fore. Here, as also within the bodily space, people make an effort to maintain normality and hide aspects of disease. This comes through in all aspects of taking drugs: as we saw in chapter six, those on ARVs, on regular vitamins and antibiotic prophylaxis, or taking ARVs for PPTCT often hide their drugs and keep their diagnosis secret. It can be seen also in people's hiding of clinic or support group visits within other tasks – predominantly women's trading activities. People's disclosure, as I will discuss below, is usually the result of illness episodes or counselling, often ARV counselling which requires disclosure to a spouse or another close family member. The process of disclosures, to trusted individuals, as a member of the support group, or at public meetings changes the identity of an individual within this space. For some, then, the domestic space can become a space of support and care; being reminded to take drugs and supported in times of illness. For others it can be a space of uncertainty and difficulty, where stigma is either a threat or a reality. As chapter three detailed many factors and axes of social difference affect these experiences. For many women hierarchies within marriage as well as within the wider household could impact significantly on their experiences, and comfort and confidence to disclose. Although the potential to be abandoned or divorced was less for men there are also gendered norms around the duty to provide for the family upon which an HIV+ diagnosis impacts negatively – seemingly making it more difficult for men to disclose within the home and admit

such 'weakness'. Here also the strength of Islamic norms of behaviour impact upon the willingness of women and men to admit to a diagnosis which in the Gambia is still associated with 'playing around'.

Coming to terms with an HIV+ diagnosis is a process which is traumatic and brings fear and shame (see for example Davies 1997). However, there are also differences between different spaces at the same time; differences in disclosure and support, differences of discourse, which shape the experience of living with HIV+. Thus in moving through these spaces people experience and understand living with HIV in shifting and changing ways. In the home, the clinic and the support group, in bodily experience and in the experience of the 'global' in this context people shape and are shaped by the discourses around HIV – what should be done, how people should behave and so on.

As the previous chapters described, people living with HIV moving through these different spaces struggle to express their needs and priorities in situations which often curtail their agency. These constraining hierarchies can be those of patronage, kinship and ethnicity which shape Gambian society, or those within and between the chains of funding and implementing agencies working around HIV in the Gambia. This is despite the fact that many programmes and projects, from the GF to local NGOs, rely on the participation of people living with HIV for legitimacy. However, it is important here to return to the idea of the portrayal of 'victims' in "modern ethnography's commitment to social criticism" (Marcus 1986; 168). My findings challenge notions of people living with HIV as 'victims'. People living with HIV are, as this study has shown, resourceful and creative people. They understand their own priorities and the difficulties they face, as described in particular in chapter seven, as well as in discussion of why people were moved to join the president's 'cure'. They work within the structures that exist in order to maximise their health and welfare, as well as shaping the relationships with HIV programmes within the Gambia as best they can.

The experience of 'spaces' in everyday life informed my fieldwork. Using this structure in writing has also caused me to reconfigure the question of how people understand HIV and treatment, and how treatment changes their experience of being HIV+. There is no single answer – movement through spaces implies flux and change.

People take on different (sick) roles, and the expectations of gender and society, differently in different environments, and in relation to the different individuals and institutions which constitute them. Thus someone who speaks vocally at a government training meeting about their treatment, their rights and responsibilities, may not have disclosed to anyone within the home. Most people's disclosure is very partial in this way, slanted towards 'easy' disclosures in official or clinical spaces, those far from the home, and away from risking their networks of kin and community by releasing stigmatising information about themselves unnecessarily. This reaffirms Bellagamba's (2009) observations about the value of secrecy in Gambian social structures, as well as the difficulties in disclosure that I described in previous chapters. Such negotiations are also an interesting comparator between low prevalence contexts such as the Gambia, and high-prevalence contexts such as Uganda, Zambia or South Africa, where similar processes are at work (Bond 2010; Richey 2011a; 2011b; Seeley and Russell 2010).

Here then, this research illustrates that although narrative is important in how people constitute themselves (see for example Mattingly 1994; Levy and Storeng 2010), this is not a constant or coherent project, but one that is constituted of many different spaces. Meinert et al. (2009) similarly describe a process through which being HIV+ is constituted within both 'home' domains and clinic and workshops. As in the Gambia this Ugandan study describes how people create certain narratives – based on diagnosis, numbers and tests – but ones which are open to reinterpretation and are never universal or complete. Ezzy's study in Australia also draws attention to the 'polyphonic' nature of HIV-illness narratives, which while taking in the uncertainty of the present place hope in the future through engagement with different kinds of organisations and through embracing the "mystery, surprise and creativity" of this uncertainty (2000; 605). Such creative and diverse use of changing roles also gives cause to reflect upon people's ability, and motivations, to move between spaces as different as the clinic and the statehouse, as well as the home and NGO offices.

8.1.2. Knowledge and the biomedical – de-re-pluralisation

In the Gambia I observed, through 2006, an on-going project of what I have argued can be seen as a project of de-pluralisation of HIV. In this, plural understandings of the illness and therapies, rooted variously in Islamic, herbal, everyday and

'traditional' knowledge and experience as well as biomedicine, were being reduced and channelled towards a view that only biomedical perspectives were appropriate and legitimate. This is part of a global project, which can be identified through looking to the 'AIDS industry' and the way it is played out in different contexts, as I described in chapter three. Specifically it can be seen in the activities of the clinics, NGOs and government agencies which are at the end of chains of global funding and policy, and in the ways these institutions interact with the support groups and their patients or clients as individuals (Cassidy and Leach 2010; Cassidy 2010).

This was necessarily an incomplete project, enacted within certain spaces. As chapter four described there are multiple systems which delineate which illnesses are 'for the clinic' and which can be treated through other means. My observations through 2006 confirmed however that for people living with HIV and linked into the clinics and support societies HIV was positioned very much 'with the clinic'. Further community focus groups also positioned HIV as an illness which was 'new' and 'for the clinic'. Despite this some people continued to use 'traditional' medicine alongside ARVs and other clinic based treatments. Many used one treatment and then another, moving between systems, to try to find a solution to their problems.

At the end of 2006 many people spoke about their experience of ARVs and recovery – perhaps not quite in the same evangelical language which Robins observed in his study of TAC activists in South Africa, but as a rebirth of sorts (Robins 2005). However, in contrast, some of these people were moved in the following months to enter the president's 'breakthrough' and spoke of their 'cure' on television, some joining the president in condemning the 'western' pharmaceuticals they had previously praised. For these individuals there were obvious issues around coercion and patronage, as well as the potential for hope and a 'cure', as described in chapter seven. Whether it was hope, coercion or a strategic move to be close to power (and associated material benefits), for some of these people this was a fatal decision.

In this setting, and in relation to the interaction between the GF-funded ARV programme and the presidential 'breakthrough', the ways in which people moved between these two specific treatment spaces illustrates, as discussed above, a creative use of the available options.

That the 'breakthrough' was defined in relation to and, predominantly, in opposition to the internationally funded ARV programme is telling. Unlike other African nations the Gambia, despite its small size and population, and relatively low prevalence, is the site of intense practice of high science – in both the GF programme, and the presence and ongoing work of the MRC[100]. Arguably, the presidential 'cure' as described in this thesis can be understood as a backlash to the power of global funding and biomedical science in the AIDS arena (see also Cassidy and Leach 2009a).

The HIV programme is also linked to international funding streams, HIV more lucrative than most. However, this money existed outside of the control of the president and political elite, although it was in the country. At the time of the 'cure' the changes in restructuring and restaffing NAS imply that regaining control over such resources may also have been a motive.

The president's 'cure' in positioning itself as an 'African' or 'Gambian' alternative is not unusual. Many healers have claimed to be able to treat or even cure HIV (Amon 2004; Hardon et al 2008). Here however the president himself put forward the 'cure', and as such it is embedded within equally powerful structures and similar levels of institutional backing to ARV treatment. As this research has shown, despite their stark differences these two treatments for HIV have relied upon similar bases for their legitimacy. The use of numbers and test results, and the cooption of the title 'doctor' imply that, as in Kevles study of the U.S., "the new politics of science is not rooted in hostility to science as such. Rather it is energised by the readiness of these various interest groups to deploy types of science – or what they call science – to suit them" (2006; 776). In the Gambia this process went unchallenged. As Richey describes in South Africa scientific "authority has been reasserted as the performative aspects of scientific credibility have been reiterated in local, provincial, and national contexts, and, in so doing, science is being made" (2008; 21). The process of delineating the boundaries of what is and is not 'science', as Richey discusses, is a complex process in which the processes of politics, power, prestige and also funding feature heavily. In

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[100] Since my fieldwork ended the MRC have closed their GUM clinic and are no longer running an HIV unit, research on HIV has also been stopped, although other research programmes continue.

this sense this research also illuminates the ways in which HIV in the Gambia and the legitimacy of treating – or 'curing' – it became a similarly complex battleground of individuals and institutions in which the people living with HIV had limited opportunities for influence.

This discussion raises important questions for international funding and the implementation of programmes such as ARV treatment, and the 'global AIDS industry's' power and pervasiveness. How can interventions such as this be so easily derailed? How was the president able to 'cure' people so publicly with so little contestation? Ferguson's arguments around "point-to-point" connectivity are relevant here (2006; 47). While the clinics, NAS or NGO offices, and to some extent the support societies can be seen as 'points' of development where global discourse and practice take hold, these exist within a sea of different and plural discourses, norms and practices. While the work of these agencies goes on uncontested it might appear that many people 'buy in', and become an effective constituency – those who are patients and people living with HIV, as well as whole communities targeted for 'sensitizations'. However such assumptions are not evidenced here. Perhaps then, with Ferguson, it is more relevant to view the presidential cure within "a much richer set of questions about transnationalism… the central effect of the new forms of transnational governmentality, if my argument is correct, is not so much to make states weak (or strong) as to reconfigure the way that states are able to spatialize their authority and stake claims to superior generality and universality" (2006; 112).

Linked to this discussion is the 'grassroots' in the Gambia, and the role of people living with HIV in activism. As discussed in chapter three and chapter seven the 'global' reaches into this local context in various ways. One of these is the expectation of activism. Internationally the activism and mobilisation around HIV and specifically around treatment has given rise to certain kinds of 'biological citizen', making claims based upon their HIV status (Rose and Novas 2005; Nguyen 2005). However, such activism is not seen in the Gambia. This is partly due to the structures of society, and hierarchical links which discourage the challenging of those in power. In general there is no history of activism in the Gambia, and even political opposition is severely constrained. Furthermore activism such as that seen in Uganda (TASO) or South Africa (TAC) is in many ways unnecessary – as the treatment programme is in

place without such mobilisation to accomplish its foundation. Activism as such is not encouraged, although collective action, in the formation of the support groups has been facilitated by various actors - from the clinics and individuals within them to NGOs and their staff. Nevertheless, as chapter seven showed, such collective action is programmised - it is not self-generating, nor does it (often) fulfil the felt needs of the group members. Here then although group members network together and with organisations within and outside the Gambia this is largely with relatively immediate material needs in mind, rather than rights, or longer-term claims.

In this, then, another aspect of the 'global assemblage' of HIV and AIDS is visible in the Gambia – by its lack. The 'AIDS Movement' as can be tracked through European and American, and later African engagements with rights and access has not spread here. The conditions which make local activism possible are perhaps not here: in terms of political activism and engagement more generally or a history of political opposition and engagement. Also, the free availability of drugs takes away an impetus to campaign for life itself, as, for example, was seen in South Africa.

However, as chapters six and seven described international patterns are taken up, in language, definitions, practices, and drugs. People define themselves as HIV+, and they connect with an amorphous array of defining measures. However, as has been described in each of the preceding chapters such definitions have proved to be more fragile, and more partial than was assumed. Here, this study has contributed in describing the multiple and interlocking frames through which people define and re-define themselves.

8.2.   Key debates

How does this thesis speak to key debates in current research and policy around HIV and AIDS? Two key debates that informed the planning of my research at the start, and which have only heightened in the last few years, concern questions of stigma and support, and of treatment and adherence. During the research the issue of disclosure came to the surface as key to both of these: as a condition of treatment access, and as a risk of exposure and so stigma. A further theme which emerged strongly during my research was that of the livelihoods of people living with HIV – both the difficulties they face in getting by, the strategies they use to gain access to resources, and

particularly those related to an HIV+ identity. In each of these areas, my findings in the Gambia both add to current debates but also serve to challenge these in particular ways.

Here I describe the ways in which my research speaks to each of these themes and asks what lessons can be learnt: in terms of policy and practice around the provision of treatment and other services for people with HIV; and the implications for the 'global' of the local understandings - both the treatment controversy which the Gambian president's challenge to international authority brings, but also the smaller scale disaffections and negotiations faced by people living with HIV. Firstly I look at stigma and discrimination, secondly the related issue of disclosure. A third section looks at adherence to ARVs, and a final section looks to the livelihoods of people living with HIV, related to their HIV+ identity.

8.2.1. Stigma

Stigma is very difficult to define. As I outlined in the discussion in chapter two, this is a complex and difficult issue which spreads into different areas of people's lives. Through this research I have shown that stigma is a very important aspect of the experience of being HIV+. Interestingly, although experienced stigma is important, and people reported many instances of ostracism and discrimination, it is more commonly self-stigma, or a fear of negative reactions which leads to an unwillingness to disclose in this context. Where negative reactions are experienced it is often close family and relations, or the close knit communities that people live within – where "people do point" – that this is experienced and most feared. Of course there are also examples of positive and supporting relationships, particularly those discordant relationships where the HIV- spouse remained with their partner, which are the counterpoint to such negative fears and experiences.

There are many reasons for these differences in people's experiences of stigma. Many factors are individual to a particular person's living arrangements, family relationships, location and networks; thus for example for some people positive and supporting relationships are possible, with family members reminding and supporting adherence and health. Yet for others, often those already vulnerable within their

household (younger women and wives, those in rented accommodation), less support is available. For others such structural factors are irrelevant; for many women the fact that their husband "did not believe" is enough. Yet broader structures in society play a large part in forming such networks and how people are able to act within them, as described in chapter five. Thus for example those people who talk about the fact that 'people do point' are fearful for good reason – many do have negative experiences, and these are often based upon ideas about HIV and its transmission which may not have a bearing upon most people's experiences.

The ways in which community views around HIV are formed are also connected to the global networks of policy and planning, and the programmes and projects that they engender. Ideas and education about HIV and AIDS – what it is, who gets it, and how it is spread are widespread.

The presidential programme also changed this considerably. In exposing people and publicising his 'cure' no one could question the existence of HIV, or of people living with HIV in the Gambia. In November 2008 one news article stated that the 'cure' had been a 'boost' for the ARV treatment programme, and an unidentified source stated that; "The [President's] treatment has improved the uptake of antiretrovirals by reducing the social stigma of HIV-positive status and by making people realise traditional treatments do not always work"[101]. All clinics, particularly RVTH, reported more people coming for VCT after the 'breakthrough' began. However, staff told me that they suspected that these were predominantly people who knew that they were positive, who had tested before but not 'accepted' their diagnosis, and so 'run away'. They believed that such people came forward in the hope of being cured. As chapter six describes staff in the clinics were often reluctant to start some people on ARVs during this period, in case they then decided to go to the president. My observations through 2007 until early 2008 also contradict this report in that the president's patients faced more stigma not less. Those who had been in to the 'cure' and seen on television continued to face severe difficulties in their daily lives,

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[101] 'GAMBIA: President's herbal HIV/AIDS 'cure' boosts ARV use' IRIN Africa, 3 November 2008 Available online; http://www.plusnews.org/report.aspx?ReportId=81266

struggling to find secure housing, or to work with their status now common knowledge and their 'cure' a matter of public discussion.

In the Gambia, due to the low prevalence rates many people (prior to January 2007) would have said that they didn't know anyone with HIV. Some also doubted its existence in the Gambia. During 2006 I often wondered at the lack of media attention to the issue – not realising the furore that was to come. At this time many people stated that they knew about HIV and AIDS, and showed a good understanding of transmission, however there were also indicators of a level of stigma and separation from those infected in the general population (Jallow 2003). Also, as discussed in previous chapters, the social structures and a positive value on silence (Bellagamba 2008) reinforce secrecy, especially where potentially damaging information about oneself is concerned.

The issue of stigma links directly to the structure of this thesis as spaces. Here it is possible to see the ways in which the degrees to which people anticipate and experience stigma in many ways form the spaces which I delineate through my chapters – those spaces in which people 'must' disclose to some degree – the clinic and support group – and those which they can protect – the home and community.

8.2.2. Disclosure

The international discourse of public disclosure of HIV status has always been one which I have struggled to understand. Why must people be exhorted to disclose – to come out? Other people living with various illnesses are not under a moral pressure to represent their condition, and to give testimony to it, to stand in public and represent their illness. Why do Gambians living with HIV feel that this is a 'good' or a 'right' thing to do? Why do the internationally based programmes that they come into contact with this fund this as an 'activity'?

These questions and the broader issue of HIV disclosure have clear links to the ways in which HIV programming, and particularly activism around HIV and AIDS, has its roots in the gay communities of the US and Europe. While such movements were successful in moving the discourse away from discussion of GRID and a 'gay plague' in the 1980s, through the disclosure strategy it is linked to 'coming out' within gay

rights activism more generally (see also Edstrom 2010). The possible meanings of such openness and exposure in African communities are very different. That such an open activist stance can be effective in gaining rights to treatment is certainly true, as for example with TAC in South Africa. However, since there is no specific activist stance for people living with HIV in the Gambia, a more spurious gain of 'giving a face to the disease' was often given as a reason for what I interpreted as a following of what 'should' be done transported to this context, among many others.

That disclosure should be positioned as a 'good' is in itself a curious artefact of the tension in HIV programming between an individualist human rights perspective and a public health perspective. In the former, 'coming out' is an empowering activity which allows the individual to move forward. By contrast a public health perspective needs disclosure to trace the contacts of those known to be infected. Gambian ideals of family and kinship, and hierarchies supported by secrecy and societal gender norms, do not fully support the use of this strategy from either perspective.

There are people for whom disclosure has 'worked', and resulted in positive and supporting relationships. There are equally others for whom disclosures are partial and emplaced – within specific spaces and relationships which they judge to be able to withstand such a revelation. From my research I would argue that the foundations and history behind the assumption of the 'good' of disclosure need to be questioned much more rigorously, and the meanings and appropriateness or otherwise of disclosure related much more carefully to particular social and cultural settings.

8.2.3. Adherence

When planning this research, during the initial stages of ARV roll-out in the Gambia, adherence figured as a potential problem (Stevens et al 2004). However subsequent research internationally confirmed that these fears were unfounded (see Orrell 2005). People in African and other resource poor contexts can and do adhere well. In the Gambia, while the clinic staff reported serial defaulters, most people I spoke to adhered to their drugs and understood the importance of continued adherence despite the difficulties.

In respect to adherence my research found that the major challenges are: around food and hunger; around secrecy and the difficulty of taking drugs where one is not disclosed, as was anticipated in the planning of this research; and in other additional costs experienced around treatment. As Hardon et al (2007) also found for three other African nations these same factors are pivotal to understand how people come to 'fail' in adherence. An additional challenge is that of 'belief', as discussed in chapter six, and how to ensure the patient's (continued) faith in ARVs. This in turn gives a basis for understanding the ways in which adherence can be supported. In the final section of this chapter I discuss the crucial issue of livelihoods further, and in particular, issues around access to food and cash.

Spaces and adherence were also linked. The experience of taking drugs and attending the clinics relate to the way in which these spaces are experienced as 'comfortable' or otherwise, and where people feel potentially at risk of exposure. Sometimes this was through the structure of the space – the waiting areas and the ways in which the space is designated and how it is interpreted, despite or because of this. For instance areas viewed as 'for HIV' included both the clinics in MRC and HoC. Both of these spaces had outside waiting areas shared with or open to people waiting for other reasons. RVTH's waiting area (although cramped and so with similar issues around being overheard) was closed to those not waiting or being seen within this clinic. Other practices – as with the colour of plastic bags for baby food for HIV+ mothers affect the experience of using these facilities, and so also people's willingness to return and to wait there for appointments when their drugs run low.

Communication between patients and clinic staff is also an issue which has been raised through this research. The almost religious aspect of 'saving' people with HIV through treatment, as well as hierarchical relations between medical personnel and patients mean that even where people are having difficulty adhering they will often not say so. As chapter six described, people do not want to let their doctors down, to be judged or, in some descriptions, to be seen to be undeserving or unworthy of their medication through not being 'serious'. Thus here it seems that rather than being the 'culture' of the Gambia which affects adherence, it is more the 'culture' and relationships of the clinic. Interestingly these emerged differently in the different clinics. While I did interview clinic staff in two of the three clinics this material could

be analysed further to look at the different experiences of different levels of staff, the beliefs they have and the ways in which these affect the patients' attitudes and 'comfort'. As both MacGregor (2010) in South Africa and Angotti (2010) in Malawi discuss, counsellors are the front line in HIV care, and they also reinterpret in their daily work the ways in which counselling 'should' be done. Both authors speak of the ways in which counsellors adapt the internationally accepted norms of the '3 C's'[102] within the constraints of practice:

> …the implementation of Western testing norms is, at times, quite different from that envisaged in official policy. The protocols that counsellors are taught do not and cannot cover all contingencies: what counsellors do in practice is necessarily discretionary (Carter, 2008; Pritchett & Woolcock, 2004). As these intermediaries implement the policies of consent, confidentiality and counselling, policies that they themselves have not designed and indeed, had their origin far from rural Sub-Saharan Africa they thus actively interpret and reframe them
>
> Angotti 2010; 992

> A shared set of counselling practices and principles has gradually been eroded, whilst the official discourse of the 'Three C's' has persisted. Public Health concerns with increasing testing and human resource limitations on the numbers of highly trained counsellors have clearly contributed to this situation…. Framed in individualist terms, the underlying concern is the creation of epidemiologically responsible citizens who would maintain a moral compliance to treatment regimes in order to address population-level public health concerns.
>
> MacGregor 2010; 131-132

Within these settings in the Gambia the roles and decisions of these frontline workers are vital. As chapter six describes the practices and reinterpretations (as well as policies such as the 'three C's') shape the interface between carer and client, and the levels of comfort and blame, and so also clinic attendance, and adherence.

In this context and as described in chapters four, five, six and seven, people have their own strategies that rely upon their own judgements, their relationships and networks. In terms of counselling, and the ways this supports people in adherence, there is much more analysis that could be done. The ways in which the culture of the clinic and the

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[102] Consent, Confidentiality and Counselling

hierarchies implicit in medical interactions may be responsible for 'hiding', is an aspect of this research which could usefully be expanded.

8.2.4. Livelihoods – HIV+ identities

Throughout this thesis the focus on the experience of people living with HIV gives a nuanced picture of the changeable identities which people take on in different circumstances. One of these is that of being HIV+. Chapters six and seven discussed the ways in which these are formed and take shape with the clinics and support groups. Chapter three described the ways in which the bodily experience of both being HIV+ and taking treatments are also formative of an HIV+ identity, while chapter four extended this into the domestic sphere. Being HIV+ is in general not a positive thing. There are however, as described in chapter seven, advantages.

People who join the support groups are linking themselves not only into a social network, but into a network of resources. By linking themselves into international funding chains they can potentially access material resources. As the previous chapter described, for many people living with HIV such links – per diems for workshops and trainings, payment for taking part in sensitisations, or even the rare chance to travel abroad to a meeting – can make up the majority of their income. That these people are almost entirely reliant on being HIV+ for their livelihood is rarely discussed. Of course the activities and trainings which are funded through the groups – soap making and tie-and-dye – focus explicitly on IGA (income generating activities). This implies an understanding by programmers of the reliance people have upon such activities, and the general context of poverty and partial employment in the Gambia.

However, in a situation of generalised poverty, with no welfare, why (and how) should HIV+ people receive extra help – that all want and many need? In my fieldwork I knew of one person who claimed falsely to be HIV+ in order to access these livelihoods. In South Africa where people living with HIV can access disability grants this debate - that more would follow should further supports for HIV+ people be available - is more developed and, it appears from the literature that such fears are unfounded (Natrass 2006; Leclerc-Madlala 2006; MacGregor 2010). However, linking any such support to CD4 counts (as in South Africa) may disincline some to adhere to ARVs, and so keep their grant (Leclerc-Madlala 2006). Alternatively such

provision could be linked to good adherence (Booth cf. Macgregor 2010; 122). From my research it seems that such payments would be more than welcomed. Those within the support groups feel that their work and contribution is undervalued, and any recompense for their time and efforts would ease their difficulties. This is both in sheer financial terms and also socially – by being able to contribute to their households from the work that they do.

Most people in the Gambia face extreme poverty and food insecurity. Those who suffer periods of ill-health become even more vulnerable, often unable to work. Within peri-urban Gambia where traditional patterns of mutual support may not function this is further exacerbated. Being able to access good food is a severe challenge for many people, one which is more pressing for people living with HIV, and more so for those taking ARVs, and my research shows, can impact upon adherence. When each person's drugs cost thousands of pounds to procure and transport, that these same patients cannot find food to eat daily is a terrible irony – and one that they themselves understand all too well.

The links between HIV and food security and livelihoods is firmly made by many authors (see for example Loevinsohn and Gillespie 2003; De Waal and Tumushabe 2003; Gillespie and Kadayala 2005; Rugalema 2000), illustrating that AIDS and livelihoods cannot be separated. This analysis is often related to the harsh realities of people failing to deal with 'shocks' and the spirals of poverty into which they fall. However, another aspect, as discussed in chapters five and seven, are the positive and reinforcing values of working and gaining both resources and security, and also confidence and self-belief. Such values in relation to the formation of support societies in Vietnam (Oosterhoff et al 2008) and to work and the 'order and control' it can bring to people in Uganda (Russell and Seeley 2009), similarly illustrate this point. Here again further research into the ways in which people are able, fully or partially, to form positive work relationships, and the way in which these are linked to the 'global' would be a further contribution to this growing literature.

In many ways the insights and lessons from the Gambia, a small low prevalence country, could seem removed from these broader issues internationally- and the debates about HIV treatment, stigma, adherence and livelihoods that swirl globally. In

particular the events which unfolded around the presidential 'breakthrough' could push the case of the Gambia to the side as an anomaly. However, as my research shows, this separation of the local and the global is a "blurry boundary" (Dry and Leach 2010; 246). Looking to the Gambian case has shown how structures – both global and local – shape the experience of being HIV+, but also that these spaces are actively and creatively shaped by those living in them. Here there are many lessons for the wider world of HIV programming, and the ways in which one-size-fits-all programming can cause distress, and also backlash, in the reactions of the powerless and the powerful in different contexts. How people in the Gambia, and elsewhere, and their priorities can break through the stronger discourses of 'global AIDS' to have their needs discussed (if not addressed) is a key question. It suggests a refocusing of attention in 'local responses' onto these priorities, rather than those set by global health and biomedicine.

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Annex 1

Timeline of research activities in the Gambia (red)
Corresponding timeline of group entry into and release from the president's 'breakthrough' (blue)

	2006				2007												2008		
	Sept	Oct	Nov	Dec	Jan	Feb	March	April	May	June	July	August	Sept	Oct	Nov	Dec	Jan	Feb	March
Interview - HIV+ SSs	■	■	■	■															
Interview - HIV+ Clinics	■	■	■	■															
Interviews (NGO/Staff/Etc)		■		■										■	■	■			
Interviews - Clinic Staff														■	■	■			
Interviews - Traditional Healers				■								■		■	■	■	■		
Focus Groups - Community											■	■	■						
PO - Home Compound	■	■	■	■	■	■	■	■											
PO - Support Groups	■	■	■	■	■	■	■				■	■	■	■	■	■	■		
PO - Clinics	■	■	■	■	■	■	■				■	■	■	■	■	■	■		
PO - trainings/workshops	■	■	■	■	■	■	■				■	■	■	■	■	■	■		
Workshops - HIV+ SSs														■	■	■	■		
Break in Fieldwork								■	■										
Timeline of presidential cure					1st Group (9)	2nd Group		3rd Group		13 leave 'cured'	1st & 2nd groups	4th Group					1 year annivers		3rd and 4th