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HIV-positive African women's engagement with HIV care in the UK during and after pregnancy

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I dedicate this thesis to my mother Nasira, a migrant pregnant woman herself nearly forty years ago, who has allowed me to learn first-hand about the strength and resilience of migrant mothers.

Declaration

I, Shema Tariq, confirm that the work presented in this thesis is my own.

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Abstract

Approximately 1400 HIV-positive women are known to become pregnant in the UK each year, the overwhelming majority being from Sub-Saharan Africa.

The overall question I pose in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? The question is addressed through a mixed methods approach. Drawing upon epidemiological data from the UK and Ireland's National Study of HIV in Pregnancy and Childhood, and primary ethnographic data, I examine key outcomes (not receiving antiretroviral therapy during pregnancy, detectable maternal HIV viral load at delivery, vertical transmission, late antenatal booking and maternal loss to follow-up from HIV care after pregnancy), as well as exploring women's experiences.

Women from Western Africa and those who had arrived in the UK after conception appeared to be at greater risk of poorer outcomes. Pentecostal beliefs in divine healing, although cited by professionals as a potential barrier to HIV care, did not necessarily prevent women from engaging with HIV services and interventions. Instead, a complex constellation of cultural and structural factors including stigma and lack of UK citizenship rights emerged as a greater challenge to engagement with care.

Women described good relationships with their multidisciplinary HIV antenatal teams that fostered confidence in medical systems. On the other hand, some reported negative experiences, particularly with regards to poor maternity care at the time of delivery and difficulties in abstaining from breastfeeding.

Overall I found that the majority of African women living with HIV in the UK engage well with HIV services and interventions during and after pregnancy, resulting in low rates of both vertical transmission and loss to follow-up after pregnancy. This highlights women's resilience and determination to engage with HIV care, despite challenges, in order to secure the health of their babies.

Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

AIC: African Independent Church

ANC: Antenatal care

ART: Antiretroviral therapy

ECS: European Collaborative Study

EDD: Estimated date of delivery

FMI: Fraction of missing information

HAART: Highly active antiretroviral therapy

HANDD: The HIV and AIDS New Diagnoses Database

HIV: Human Immunodeficiency Virus

HPA: Health Protection Agency (Public Health England (PHE) from April 2013)

ICH: Institute of Child Health

LTFU: Loss to follow-up

MCH: Maternal and child health

MICE: Multiple Imputation by Chained Equations

MNAR: Missing Not At Random

MSM: Men who have sex with men

MTCT: Mother-to-child transmission

NHS: National Health Service

NSHPC: National Study of HIV in Pregnancy and Childhood

PMTCT: Prevention of mother-to-child transmission

SOPHID: Survey of Prevalent HIV Infections Diagnosed

TCPM: The Triumph of Christ Pentecostal Ministry

UCL: University College London

UK CHIC: The UK Collaborative HIV Cohort Study

VL: Viral load

VT: Vertical transmission

1

Introduction

Summary

This thesis explores how African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy. In this introductory chapter I provide background to my subject of inquiry. I start by using a vignette from my own clinical practice as an entry point into my work. I then describe the broader epidemiological context of HIV both globally and in the UK before specifically focusing on HIV in African communities in the UK. Following this I provide an epidemiological overview of HIV and pregnancy in the UK, before summarising the key components of clinical management of pregnancy in the context of HIV. I proceed to outline the rationale behind my work by highlighting the paucity of work in HIV and pregnancy that focuses on mothers, and providing a critique of the use of "Black African" as an analytic tool to examine difference. After introducing the research questions posed in this thesis, I summarise three key theoretical frames that underpin my work. I then conclude this introductory chapter with an outline of the overall structure of the thesis.

1.1 Pauline[1]

Several years ago whilst working as a junior doctor in an HIV antenatal clinic in London, I met Pauline, a 32-year-old woman from Sierra Leone. Some months earlier she had been diagnosed with HIV during a routine screening blood test in pregnancy. When the HIV specialist midwife gave her the diagnosis, it came as a shock and she had found it hard to come to terms with it, subsequently failing to attend any further antenatal appointments. She later went on to have a stillbirth as a result of an HIV-related infection of the placenta.

A few months later she attended the hospital's general antenatal clinic in the early

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[1] Names and some other details have been changed to protect confidentiality.

stages of pregnancy. The midwives, knowing her HIV status, offered her an appointment with the HIV specialist midwife. However, Pauline declined. She believed that the specialist midwife had precipitated her stillbirth by giving her her diagnosis. For Pauline, HIV was a "curse" that the midwife had placed upon her to the detriment of her baby. She did not want to discuss her HIV diagnosis or engage with the possibility of taking treatment, instead insisting on attending the general antenatal clinic and seeking "healing" through prayer. At this point Pauline was significantly immunocompromised and was at risk of severe opportunistic infections. Furthermore, she had already lost one baby as a result of a potentially reversible HIV-related complication.

This complex situation would usually have been best managed by an HIV antenatal specialist team but this was not feasible in view of Pauline's reluctance to discuss her diagnosis with anyone. At some point, we decided as a team that I would start looking after her as an "infection" doctor. Over the following months Pauline and I made tentative steps towards getting to know each other. We talked about how to make her body and immune system "stronger". I was careful not to mention the word "HIV"; Pauline, for her part, slowly began to open up to the possibility of taking "immune-boosting" drugs. During this time I was struck by Pauline's social isolation. With no friends or family around her, her only source of support was her partner who also believed in a spiritual aetiology of HIV, declining HIV-testing himself in favour of prayer. Furthermore she was overwhelmed by her precarious financial situation and anxieties about what would happen now that her visa had expired.

Throughout Pauline's pregnancy we negotiated a difficult terrain between our differing "explanatory models"[2] of HIV. However, together we reached a point where her HIV was well controlled on HIV medication, despite never discussing HIV explicitly, and she delivered a healthy HIV-negative baby girl. After delivery, Pauline brought her daughter in for her routine HIV test and came to the HIV clinic for her own HIV care. However a few months later Pauline stopped her medication and her attendance at the clinic became more erratic until her visits finally tailed off and we were unable to contact her again.

Towards the end of my fieldwork, a colleague mentioned to me that Pauline had been

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[2] Kleinman and colleagues were the first to highlight the role of patients' and healers' (used in the broadest sense to also refer to biomedical doctors) discordant explanatory systems as a barrier to effective delivery of healthcare (Kleinman, et al. 1978).

admitted to hospital after years of not being seen. She had kidney failure as a result of advanced HIV infection. At this point she declined any further treatment, explaining that she and her husband were concerned that members of her church might see her attending for HIV care. She discharged herself with the hope of finding a cure through prayer.

Over the past ten years I have seen many women with similarly complicated journeys through pregnancy and motherhood. However Pauline's story has stayed with me, reminding me that HIV in pregnancy is embedded within a complex matrix of biomedical, social and cultural factors that are often poorly understood, and prompting me to develop the work I present in this thesis.

1.2 Global epidemiology of HIV

Since the first reports in 1981 of a cluster of cases of *Pneumocystis Carinii* pneumonia in young gay men in the United States (Centers for Disease Control 1981), HIV has become a global epidemic with 34 million people living with HIV worldwide by the end of 2011 (UNAIDS 2012). Although rates of new HIV infections have fallen in recent years, the number of people living with HIV globally continues to increase, largely as a result of the scale-up of antiretroviral therapy (ART)[3] and the consequent decline in HIV-related deaths (Ibid.). In the past decade there has been a twenty-fold increase in the coverage of ART worldwide, with more people initiating ART in 2011 than at any other time previously (Ibid.).

Sub-Saharan Africa bears a disproportionate burden of the disease with 23.5 million people estimated to be living with HIV by the end of 2011, 69% of the global total, and 70% of all HIV-related deaths worldwide (Ibid.). Throughout most of the region the number of people newly infected with HIV is now stabilising or declining as a result of widespread HIV prevention interventions including condom promotion, male circumcision and the use of ART. Although there has been a rapid expansion in ART coverage across the continent, it remains low at 54% (Ibid.). There are important variations in the HIV epidemic *within* Africa with prevalence[4] ranging from less than 5% in Western and Central Africa to over 20% in Lesotho, Botswana and Swaziland (Ibid.).

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[3] Antiretroviral therapy is the term for medication used to treat HIV. There are currently five classes of medication available with standard ART comprising three antiretroviral agents from at least two different classes.

[4] The prevalence is the proportion of the population found to have HIV.

The HIV epidemic in Sub-Saharan Africa is predominantly heterosexual, with women representing 58% of all people in the region living with HIV. The preponderance of women in the HIV epidemic in Sub-Saharan Africa is due to a number of intersecting factors including women's physiological vulnerability to HIV[5] and social determinants such as gender inequality, poverty, poor access to education and gender-based violence[6].

1.3 Epidemiology of HIV in the UK

As in other parts of the world, the number of people living with HIV in the UK continues to grow (figure 1.1). However, the HIV epidemic is relatively small with an estimated 96,000 people living with HIV in the UK by the end of 2011 of whom 20,200 (21%) were African-born heterosexual women. Despite the increasing prevalence of HIV, the number of HIV-related deaths and AIDS diagnoses remains stable as a result of the widespread availability of highly active antiretroviral therapy (HAART)[7] (figure 1.1). In the UK, HIV prevalence is elevated both among men who have sex with men (MSM) and African-born heterosexual women and men, with the largest numbers of people living with HIV coming from these groups (figure 1.2).

The total number of new HIV infections in the UK in 2011 was 6280. There has been a consistent decline since a peak in 2005 (figure 1.1), mainly due to a decrease in reported diagnoses among heterosexuals born in areas of high HIV prevalence. It is important to note that the number of new diagnoses in MSM has increased year on year since 2007, with 2011 seeing the highest ever number of new diagnoses among MSM in the UK.

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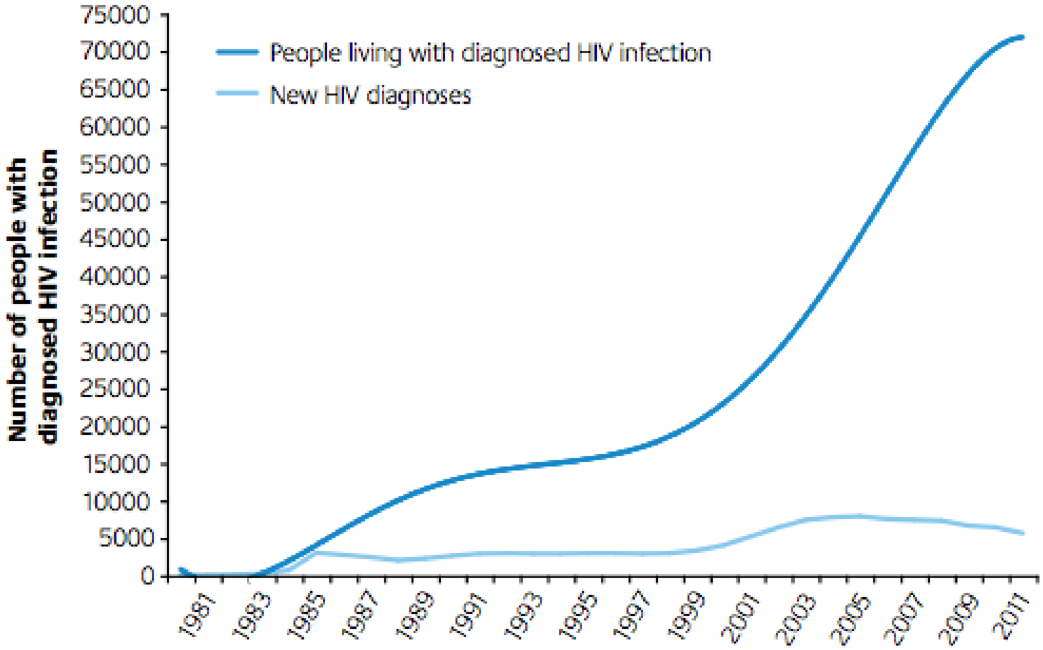
[5] Women's biological vulnerability to HIV acquisition is thought to be secondary to hormonal changes, vaginal environmental factors and increased co-infection with other sexually transmitted infections, (Quinn, et al. 2005).

[6] A background paper prepared on behalf of the Salamander Trust providing an excellent overview of current knowledge of violence against women in the context of HIV is available at http://www.salamandertrust.net/resources/VAPositiveWomenBkgrdPaperMarch2011.pdf (accessed 30 July 2013).

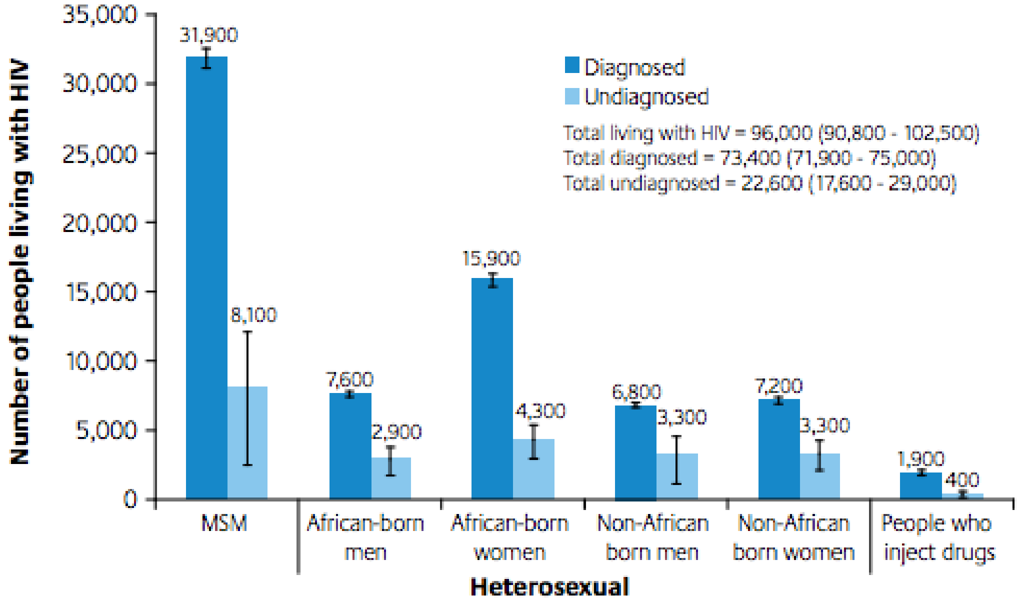
[7] HAART is the combination of antiretroviral agents, usually from at least two different classes, to treat HIV.

Figure 1.1: Annual number of people living with HIV infection and newly diagnosed with HIV in the United Kingdom, 1980-2011



Source: http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317137200016 (accessed 30 July 2013).

Figure 1.2: Estimated number of people living with HIV (both diagnosed and undiagnosed) in the United Kingdom, 2011



Source: http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317137200016 (accessed 30 July 2013).

Within England there is substantial geographical variation in the HIV epidemic. The prevalence of diagnosed HIV infection in London is much higher than any other region in England at 5.4 per 1000, and is more than 2.5 times the prevalence rate in England as a whole (Public Health England 2013). In 2011, new HIV diagnoses in London comprised over half of all new diagnoses in England whilst those with living with diagnosed infection (n=31,147) represented just under half of all patients accessing HIV care in England (Ibid.)

1.4 HIV in African communities in the UK

The Black African community[8] bears a disproportionate burden of HIV disease in the UK with a prevalence of 37 per 1000 persons, over thirty times higher than in the UK population overall (Health Protection Agency 2012). In 2011 HIV prevalence among Black African women was 50 per 1000, twice as much as the prevalence in Black African men (Ibid.). Among the 2990 new diagnoses of HIV infection due to heterosexual contact, nearly 60% were among Black Africans, the majority of whom were born outside the UK (Ibid.). In earlier years of the HIV epidemic in the UK it was believed that the majority of Black Africans acquired their HIV abroad. However, there is evidence that an increasing number of infections are acquired in the UK rather than abroad (Rice et al. 2012).

Nearly a third of people living with HIV in the UK were born in Africa. There were 30,700 Africans estimated to be living with HIV in the UK by the end of 2011, two thirds of whom were women (figure 1.3). The majority of Africans newly diagnosed with HIV in the UK originate from East Africa, although the epidemic has become more diverse over time. The proportion of Africans diagnosed with HIV who are from East Africa has fallen from just under 75% in 2001 to approximately 50% in 2010, whilst in the same time period there was a significant increase in diagnoses in West Africans to a point in 2010 when almost one in three Africans diagnosed with HIV in the UK were West African (Meaghan Kall, Public Health England, personal communication, 25 June 2012)[9].

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[8] "Black African" here refers to the ethnic category used in the UK Census since 1991. It is based on self-reported ethnicity as belonging to a Black African group, rather than country of birth. This is discussed in detail later in this chapter.

[9] The trends in region of birth in Africans diagnosed with HIV in the UK firstly reflects the changing geographical distribution of the disease in Africa, which was initially concentrated in Eastern Africa earlier in the epidemic before becoming more widespread. Secondly it reflects underlying changes in migration patterns from Africa to the UK (Owen 2009).

Studies have shown that African[10] patients are more likely than others to present to medical services at a later stage of HIV infection, with advanced disease and greater immune suppression (Burns et al. 2001, The UK Collaborative Group for HIV and STI Surveillance 2005). This is due to a number of factors including perception of low risk, fear of stigma and discrimination, lack of HIV testing in general medical settings and anxieties regarding medical bills for HIV care (Burns et al. 2007, Thomas et al. 2010). African heterosexual patients are also more likely to be lost to follow-up from HIV care than white MSM. Disengagement from medical services could be due to institutional barriers such as lack of entitlement to free care, cultural factors leading to treatment concerns (Erwin et al. 1999), or emigration (Rice et al. 2011). Many Africans living with HIV in the UK have a high level of social need (Weatherburn et al. 2003, Ibrahim et al. 2008) including financial difficulty (Weatherburn et al. 2003), social isolation (Doyal 2009) and insecure immigration status[11] (Allan et al. 2005, Cherfas 2006). The medical and social care of HIV-positive asylum seekers may be further disrupted as a result of compulsory dispersal[12] to areas of the UK which have few HIV and voluntary sector services (Creighton et al. 2004). All of these factors are likely to impact on patients' access to healthcare and may result in them seeking alternative treatment either in lieu of, or as an adjunct to, services provided within the NHS (Erwin et al. 1999, Thomas 2010).

1.5 HIV and pregnancy

Transmission of HIV from a mother to her infant is known as vertical transmission[13] and occurs during pregnancy, during delivery, or postnatally through breastfeeding (Newell 1998). In 2011, 333,000 children were estimated to have newly acquired HIV worldwide. The number of new infections in children in 2011 was substantially lower than in 2003 as a result of widespread efforts to prevent vertical transmission (UNAIDS 2012). Over 90% of these new HIV infections were in children living in Sub-Saharan Africa. Although the number of new infections in children has fallen by 24% since 2009

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[10] In this section I draw upon findings from work conducted within both Black African and African-born communities, reflecting a lack of consensus on how to explore ethnic disparities in HIV outcomes.

[11] Throughout this thesis I use *secure* immigration status to describe being a UK citizen, a recognised refugee or having exceptional or indefinite leave to remain. Anyone not in these categories is defined as having insecure immigration status.

[12] Since 2000 the UK Home Office policy has operated a compulsory dispersal policy where asylum seekers are housed on a no-choice basis in locations mainly situated outside of London and the South East region of the UK in an effort to distribute housing, social and financial pressures amongst local authorities throughout the country.

[13] It is also known as mother-to-child transmission (MTCT), however I avoid this terminology in this thesis as result of concerns that it assigns blame to mothers, constructing them as "vectors of infection". HIV activists advocate the use of more neutral language that focuses on the event (Dilmitis, et al. 2012).

in the region overall (UNAIDS 2012), there is important variation across countries. The vertical transmission rate in Southern Africa, which also has the highest coverage of ART for the prevention of vertical transmission[14], has declined faster than in Central and Western Africa where coverage is much lower (Ibid.). For the rest of this section I will focus on HIV and pregnancy within the UK.

1.5.1 HIV and pregnancy in the UK

The overall prevalence[15] of HIV among women giving birth in England was 0.22% in 2011 (Health Protection Agency 2012) [16]. This is an increase from 2002 when the prevalence was 0.15% but it has been stable in recent years at 0.21-0.22% (Ibid.). Within England there is substantial geographical variation with regards to the prevalence of HIV among women giving birth with London having the highest prevalence at 3.5 per 1000, compared with 1.6 per 1000 in the rest of England (Ibid). Pregnant women born in Sub-Saharan Africa have the highest prevalence of HIV at 2.3% compared with 0.05% in women born in the UK and 0.58% in those born in other parts of the world[17].

The number of pregnancies in women with *diagnosed* HIV-infection reported to the UK and Ireland's National Study of HIV in Pregnancy and Childhood (NSHPC) has increased 17-fold from 82 in 1990 to over 1400 a year since 2006[18], with the sharpest rise occurring between 1999 and 2003 (Townsend et al. 2008b). The increase in pregnancies reported to women diagnosed with HIV is due to a number of factors including the steep rise in heterosexually acquired HIV in the 1990s (Health Protection Agency 2006), the introduction of routine antenatal screening for HIV in the early 2000s, and the introduction of HAART which has improved prognosis in terms of women's survival and reducing the risk of vertical transmission, affording greater reproductive opportunity. This is reflected by the increase in pregnancy rates between 2000 and 2009 in women attending for HIV care in thirteen UK clinics (Huntington et al. 2013), with women of Black African ethnicity being more likely to become pregnant than their White counterparts (Ibid.). Another important contributing factor to the

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[14] As discussed later in this section, ART is a cornerstone in the prevention of vertical transmission of HIV.

[15] The proportion of pregnant women found to be HIV-positive through testing newborn infants for the presence of HIV antibodies.

[16] This includes women with diagnosed and undiagnosed HIV infection.

[17] Data obtained from http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1287144874352 (accessed 23 September 2013).

[18] See NSHPC summary slides from July 2013, available at http://www.ucl.ac.uk/nshpc/slides (accessed 23 September 2013).

increase in pregnancies reported in HIV-positive women is the rise in sequential pregnancies[19], with nearly 50% of pregnancies reported to the NSHPC in 2011 being in women who had had a previous reported pregnancy (Tookey 2013). The proportion of women reported as pregnant to the NSHPC who were diagnosed with HIV prior to conception has increased from 40% between 2000 and 2003 (Townsend et al. 2008b) to just over 80% in 2011 (Byrne et al. 2013), a reflection of both the increase in HIV-testing in a range of medical settings including antenatal clinics and the rise in second or subsequent pregnancies. Routine antenatal testing for HIV has been highly successful with 95% uptake of testing and 95% of women with HIV being diagnosed by the time of delivery[20]. Diagnosis during pregnancy is often made at an early stage of HIV disease, with only 11% of women having symptomatic HIV or AIDS (Townsend et al. 2008b). The increase in diagnoses prior to conception has been accompanied by an increase in the proportion of women who are on ART at conception to nearly 40% (Townsend et al. 2013).

There have been significant demographic changes in women reported to the NSHPC as pregnant over time. Pregnancies in women reported to have acquired HIV through injecting drug use (or from an injecting drug using partner) fell ten-fold from 1990, to less than 5% in 2004 to 2006 (Townsend et al. 2008b). In the same time period, the proportion of reported pregnancies that were in women born in Sub-Saharan Africa increased significantly from just under 50% in 1990 to nearly 80% in 2004 to 2006 (Ibid.) and has stabilised at this level since then, reflecting the overall trends in HIV epidemiology described earlier in this chapter.

1.5.2 Clinical management of pregnancy in the context of HIV

The risk of vertical transmission is estimated to be between 25% and 40% in the absence of interventions (Newell et al. 1997). Important interventions to reduce vertical transmission[21] include screening for HIV in early pregnancy (Townsend et al. 2008a), delivery by elective caesarean section[22] (Kind et al. 1998) and the avoidance of breastfeeding (Nduati et al. 2000). The cornerstone of the prevention of vertical

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[19] Women having a second or subsequent pregnancy reported to the NSHPC since their HIV diagnosis.

[20] See NSHPC summary slides from July 2013, available at http://www.ucl.ac.uk/nshpc/slides (accessed 23 September 2013).

[21] Important interventions to prevent HIV in childhood also include addressing the broader context of women's reproductive healthcare including the prevention of HIV in people of reproductive age and the prevention of unplanned pregnancies (Abrams 2004).

[22] Although recent data show that rates of vertical transmission in women who have controlled HIV-infection on ART have been shown to be similar in vaginal deliveries and those by elective caesarean section (Townsend, et al. 2013).

transmission of HIV is the use of ART in pregnancy, which has been the major driver in the decline of new infections in children globally Over the past two decades, the use of single antiretroviral agents (Connor et al. 1994, Guay et al. 1999) which were the first regimens to be found to be effective for the prevention of vertical transmission, has been superseded by the use of HAART which has largely contributed to the decline in rates of transmission (Cooper et al. 2002, European Collaborative Study 2005, Tonwe-Gold et al. 2007).

In the UK there is clear national guidance for the management of HIV in pregnancy (figure 1.3). The approach comprises early and universal screening for HIV in pregnancy (National Institute for Health and Clinical Excellence 2008), timely initiation of ART, appropriate management of delivery, ART prophylaxis to the infant, and the avoidance of breastfeeding (Taylor et al. 2012) . HAART is the most commonly used ART regimen in pregnancy in the UK (Townsend et al. 2008b), with an aim to start treatment by week twenty-four of pregnancy at the latest (Taylor et al. 2012) and earlier if the mother's HIV viral load is high (Read et al. 2012). Pregnant women living with HIV are expected to attend antenatal appointments more frequently than women without any medical complications, as they require blood test monitoring of response to treatment and possible side effects. The management of HIV in pregnancy is complex requiring careful consideration of obstetric, paediatric and HIV-related issues, as well as the provision of emotional and social support. National guidelines therefore recommend that antenatal HIV care be delivered by a multidisciplinary team comprising, at the very least, an HIV specialist doctor, an obstetrician, an HIV specialist midwife and a paediatrician[23] (Taylor et al. 2012) . The combination of the above interventions has been successful, resulting in the UK having the lowest vertical transmission rate in the world in recent years at 0.5% (Townsend et al. 2013).

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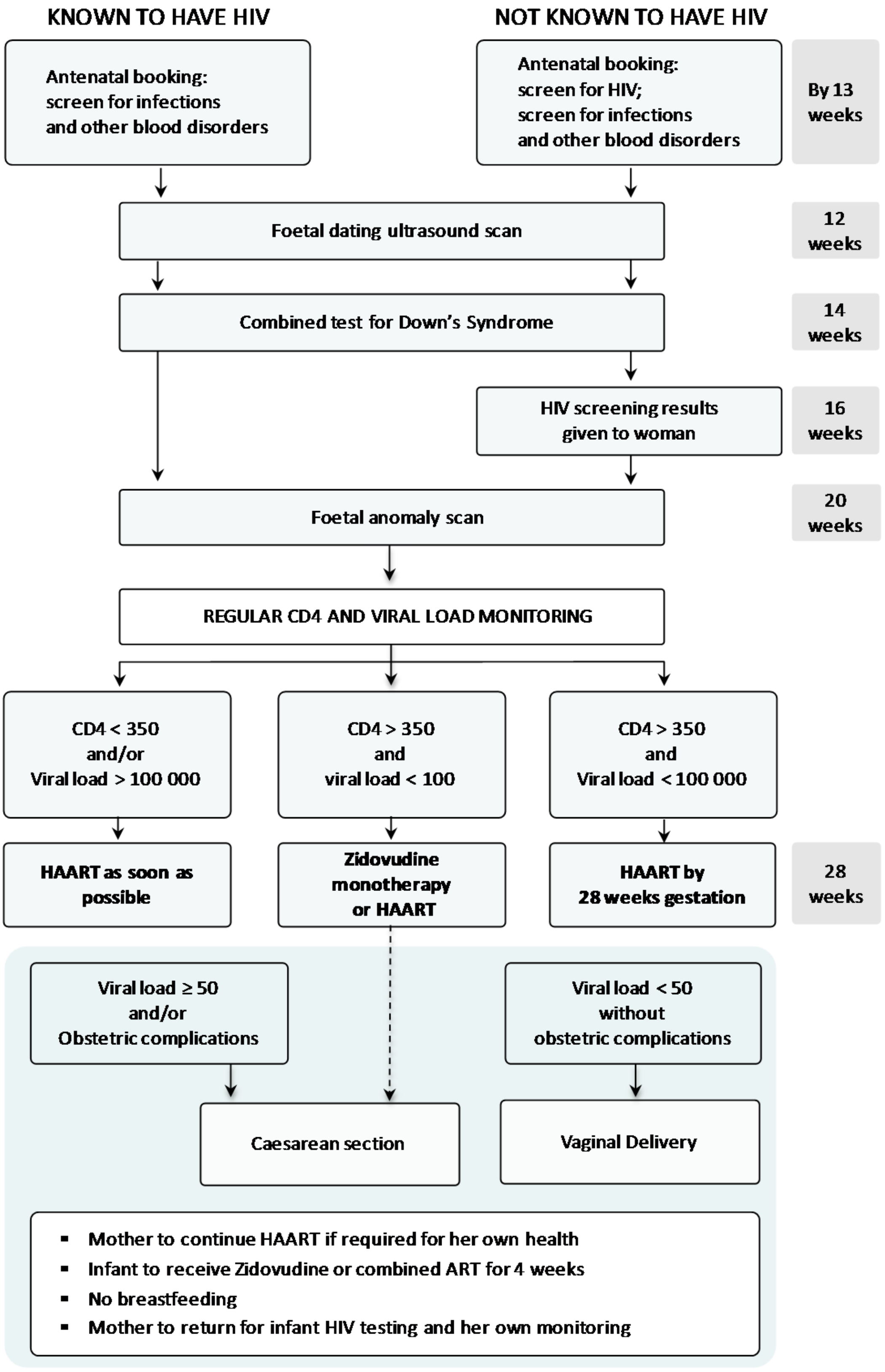
[23] The multidisciplinary team often extends beyond this core group to include voluntary and peer support professionals, social workers, legal advocates, clinical psychologists, clinical nurse specialists as well as others.

Figure 1.3: Antenatal management of women living with HIV in the UK



Source: (Taylor et al. 2012).

1.6 Rationale for my research

So far in this chapter I have described the changing epidemiology of HIV in the UK, placing it in a broader global context. I have highlighted the disproportionate burden of disease borne by African communities living in the UK, especially women, and the increasing diversity in terms of African region of birth. Since the early 1990s there has been a rise in the number of pregnancies reported in women living with HIV as a result of the introduction of routine antenatal HIV screening and the increased reproductive opportunities afforded by the advent of HAART. In recent years, over 1400 pregnancies a year in HIV-positive women have been reported to the UK and Ireland's national surveillance programme; the majority in women of Black African ethnicity. This epidemiological data allows us to begin to appreciate the importance of pregnancy in African women living with HIV as an object of inquiry. I will now build upon this by summarising two other key areas that have informed the development of my work.

1.6.1 Where is the M in MTCT?

The global decline in rates of vertical transmission and the current UK rate of 0.05% should rightly be hailed as a success. However, to focus solely on vertical transmission risks overlooking other important aspects of pregnancy in the context of HIV. In their 1985 paper, Rosenfield and Maine (Rosenfield et al. 1985) posed the following question: where is the "M" in MCH? The authors drew attention to the fact that most maternal and child health (MCH) programmes tended to focus upon the child, often considering women "only in relation to improving infant outcomes" (Ibid.: 84). Nearly two decades later they revisited this question, this time framing it within the HIV epidemic (Rosenfield et al. 2001). The authors argue that MCH programmes and the academic community have focused their attention on the health of infants and minimising the risk of vertical transmission whilst overlooking the multiple ways in which HIV affects their mothers. Indeed a cursory search for literature on HIV and pregnancy will reveal the preponderance of work on vertical transmission and other infant-related outcomes such as preterm delivery and congenital abnormalities. A recent scoping review of reproductive health research in HIV (Loutfy et al. 2012) has underlined this neglect of expectant mothers' health, identifying critical gaps in current knowledge on key aspects of HIV and pregnancy including maternal health outcomes, optimal methods of infant feeding, and social and psychological aspects of motherhood. Access to healthcare and engagement with services is a critical factor in the health of women living with HIV and their children as highlighted by a retrospective review of cases of vertical transmission in the UK (National Study of HIV in Pregnancy and Childhood (NSHPC) et al. 2007). This report identified high levels of social need among mothers whose children acquired HIV and highlighted the significant role of delayed access to services and poor communication between mothers and healthcare professionals. A review of the theoretical underpinnings of current literature on the prevention of vertical transmission has revealed a paucity of studies that explore social determinants of health such as gender inequality and poverty, arguing for work that engages with HIV and pregnancy from a perspective of *structural violence*[24] (Hampanda 2012).

1.6.2 Moving beyond the term Black African

A central aim of public health research, including epidemiology, is to investigate differences between populations in order to address health inequality and inform public health policy. In the past two decades, ethnicity has become a key area of interest[25] resulting in a proliferation of studies that explore associations between ethnicity and health[26]. This work has revealed important health disparities such as increased mortality rates in the UK among those born outside the country (Davey-Smith et al. 2000) and increased rates of hypertension, diabetes and obesity in people of African and Asian ethnicities when compared with white Europeans (Landman et al. 2001). In the area of sexual and reproductive health, studies in the UK have shown differences in rates of sexually transmitted infection across ethnic groups (Lacey et al. 1997) and access to antenatal care in the UK (Rowe et al. 2008, Jayaweera et al. 2010).

Ethnicity has been defined as “the social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including language, diet, religion, ancestry, and physical features traditionally associated with race” (Bhopal 2004). Unlike arguably more objective variables such as age and sex, ethnicity is a complex and contested social construct that defies objective

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[24] The theoretical concept of structural violence will be described in detail later in this chapter. Briefly, it refers to the ways in which political, social and cultural structures act to cause harm.

[25] This increasing focus on ethnicity in health research has its roots in feminist movements of the 1970s that highlighted the importance of difference, and a subsequent move towards the inclusion of minority groups in research and an understanding of their differences compared with majority groups (Epstein 2007). This has coincided with rapid globalisation and unprecedented movements of people transnationally with a consequent need to explore differences among groups with varying geographical origins, cultures and migration histories.

[26] In the United States there has been a parallel surge of interest in the associations between race and health. The use of race in American literature has a particular socio-historical origin that is context-specific and of limited relevance to work in the UK.

measurement. Several authors have highlighted important limitations of the use of ethnicity in health research (Bhopal et al. 1998, Aspinall 2002, Bhopal 2004, Mateos et al. 2009). These authors highlight a lack of critical engagement with ethnicity as a construct. Ethnicity is rarely explicitly defined in papers and there is a propensity for it to be conflated with race. Furthermore the lack of a clear consensus regarding ethnic categorisation has led to a lack of standardisation in ethnic groups across studies making comparison difficult[27] and little description of methods used to ascribe ethnicity to individuals. However, perhaps most importantly, ethnicity is often used with little justification for it as a focus of interest or explanation of observed differences. It has a tendency to be deployed as an explanatory variable in itself without a discussion of whether differences are attributable to biological, environmental, social or cultural factors.

The most commonly used ethnicity categories in the UK are derived from the decennial England and Wales census and are described in table 1.1. Ethnicity was first recorded in the 1991 England and Wales Census, with the same categories rapidly adopted throughout the public sector before being introduced into the routine monitoring of hospital patients in 1995 (Bhopal et al. 1998). This has resulted in an "uncritical feast" on new sources of NHS ethnicity data (Kesby et al. 2003). The use of census-derived ethnicity categories within healthcare is problematic in that it is a "borrowed system of classification" (Pfeffer 1998). It was developed for administrative and political purposes with a consultation process pertaining to these uses alone (Gill et al. 1995), not to its use in health research.

The emergence of a distinct "Black African"[28] ethnic category in the UK dates back its inclusion in the1991 census and relies on an individual's self-defined ethnicity as belonging to a Black African group, rather than being based on country of birth. It is commonly used to denote people of Sub-Saharan African origin and is widely used in policy and health research in the UK, assuming the status of "social category" (Aspinall et al. 2011). Black African has become a standardised term in demographic and health research in the UK (Ibid.) and studies that disaggregate this category remain rare. However its use in health research is problematic for a number of reasons. As a term

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[27] For example, in the work I cite earlier in this section on ethnic disparities in sexual and reproductive health a variety of terminology are used including "African", "Black African" and "Non-UK Black".

[28] Throughout this thesis I avoid using capitalised phenotypic descriptions of ethnicity that can reinforce colour of skin as dominant markers of identity. I only used them when citing work that specifically deploys these terms.

that refers to outmoded notions of phenotypic difference, it can be perceived as offensive to some people from African communities (Agyemang et al. 2005) and may not be how people would choose to identify themselves (Bhrolcháin 1990). Furthermore it is a broad category that pertains to a group of people who were born in, or have antecedents in, a continent comprising fifty-five countries and thousands of languages and dialects. The use of Black African as an ethnic category elides vast differences in religion, diet, migratory experience, education, language, kinship groups and health beliefs (Elam et al. 2001). Furthermore it does not differentiate between first, second and third generation migrants whose experiences and health may differ. We know from rare studies that have presented disaggregated data by country of birth that there are disparities *between* groups of Black Africans in the UK in terms of health outcomes such as rates of TB and HIV (Aspinall et al. 2011). The uncritical use of the category "Black African" therefore risks obscuring important differences that may be used to inform public health policy.

In this thesis I aim to engage with the concept of ethnicity critically to explore social and cultural differences that may contribute to disparities in outcome and experiences of pregnancy in HIV-positive African women. Rather than using the term Black African, I use “African" to describe women who were born in Sub-Saharan Africa and have defined themselves as being Black African[29]. I have disaggregated data by African region of birth[30], whilst remaining aware that this approach itself has weaknesses as regional groupings are based on national borders that were often created in the context of colonisation and may have limited anthropological value. I use African regions of birth pragmatically as a heuristic device to explore cultural and social differences among African women, conscious that smaller groupings such as country of birth may not be feasible for epidemiological analyses and may also risk identification of individuals in groups of very small numbers.

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[29] Ethnicity data are collected in the NHS by asking patients to record their ethnicity themselves according to England and Wales census categories. Ethnicity cannot be attributed to a patient on their behalf by staff.

[30] These groupings are based on United Nations regional groups and are described in Chapter Three (table 3.4: 71).

Table 1.1: Classification of ethnicity in the 2011 England and Wales Census

- **White**
  - English/Welsh/Scottish/Northern Irish, British
  - Irish
  - Gypsy or Irish Traveller
  - Any other White background
- **Mixed/multiple ethnic groups**
  - White and Black Caribbean
  - White and Black African
  - White and Asian
  - Any other Mixed/multiple ethnic background
- **Asian/Asian British**
  - Indian
  - Pakistani
  - Bangladeshi
  - Chinese
  - Any other Asian background
- **Black/African/Caribbean/Black British**
  - African
  - Caribbean
  - Any other Black/African/Caribbean background
- **Other ethnic group**
  - Arab
  - Any other ethnic group

Source: 2011 Census Programme 2009.

I also present data disaggregated by duration of residence in the UK, hypothesising that this may be associated with immigration problems and poorer access to health services. A recent paper in the Lancet states that undocumented migrants face the greatest difficulties in accessing health services but that evidence on the links between migration and health is lacking due to the absence of migration-related data on health information systems (Rechel et al. 2013). Doctors of the World's[31] 2013 report of patients accessing their services in fourteen cities across Europe (including London), many of whom were undocumented migrants and asylum seekers, found high levels of psychosocial need (Chauvin et al. 2013). Over 90% of their patients reported barriers to accessing healthcare with nearly 60% describing difficulties in accessing antenatal care. The main obstacles reported included lack of knowledge of healthcare systems, being denied care

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[31] Doctors of the World/Médecins du Monde is a global organization which delivers healthcare to vulnerable people affected by war, natural disaster, hunger, poverty or exclusion. See http://doctorsoftheworld.org.uk/pages/about-us.

and being unable to pay for care.

Finally, I contextualise my epidemiological findings with qualitative data in order to explore underlying mechanisms for observed differences. I present this thesis as a response to the following call to action in a wide-ranging review of literature on sexual and reproductive health of migrants in resource-rich settings:

> "Challenges will only be overcome if more studies are conducted with an inter-disciplinary focus on migrant reproductive health. These should be both quantitative, such as epidemiological surveys with an appropriate disaggregation of different migrant populations, and qualitative, or ethnographic, in character. While the former would enable the collection of new data on migrant populations and thus improve our understanding of the reproductive health issues that confront them, the latter would deepen our knowledge of the socio-economic, political and cultural forces that contribute to reproductive health inequities between specific migrant groups and their hosts."
>
> (Georgiadis 2008: 22)

1.7 Research question

The overarching research question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy?[32] The three specific questions posed are:

1. Are maternal ethnicity, African region of birth and duration of residence in the UK associated with:
    a. Not receiving ART during pregnancy
    b. Detectable maternal HIV viral load at delivery
    c. Vertical transmission of HIV
    d. Late antenatal booking

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[32] I use the terms "living with HIV" and "HIV-positive" interchangeably throughout this thesis. There have been important critiques of the term "HIV-positive" that point to the relegation of the individual and the removal of agency and a suggestion that it is substituted with "living with HIV" (Dilmitis et al. 2012). On the other hand, the term has been employed by many HIV activists since the beginning of the epidemic. My decision to use both reflects this tension and my own uncertainties about finding the 'right' term.

    e. Loss to follow-up from HIV care in the year after pregnancy

2. What are the *mechanisms* underlying associations between clinical and service outcomes, and maternal ethnicity, African region of birth and duration of residence in the UK?

3. What are the *experiences* of African women living with HIV during and after pregnancy?

Understanding engagement with care during and after pregnancy in HIV-positive African women living in the UK involves exploring clinical outcomes; access to services; beliefs about illness, health and childbearing; and lived experiences. To explore this complex and multidimensional research question I use a mixed methods approach combining quantitative and qualitative methods informed by epidemiology and anthropology respectively.

1.8 Theoretical frames

Having outlined the rationale for this study and presented my research questions, I will now provide a summary of three key theoretical frames that inform my qualitative analyses and the synthesis of the quantitative and qualitative data in subsequent chapters. The often interconnected concepts of diaspora and globalisation, structural violence, and stigma are important anchors, repeatedly referred to at several points in this thesis.

1.8.1 Diaspora and globalisation

The term *diaspora* is defined by the Oxford English Dictionary as the "dispersion or spread of people from their original homeland" (2011). Classically, the term has been associated with the archetypal Jewish and Greek diasporas, its use historically carrying with it notions of exile and longing (Butler 2001). Since the 1980s there has been a proliferation in its use, both academically and through people's self-identification as part of diasporic groups, resulting in a degree of conceptual ambiguity (Ibid.). It is important to be clear about the distinct nature of diaspora compared with other movements of people. Although diaspora involves migration, not all migration results in diaspora. Butler identifies the distinct characteristics of diaspora as dispersal to more than one destination, a relationship to an actual or imagined homeland, an ethnonational consciousness, and a collective history of group dispersal (Ibid.). The notion of diaspora is a conceptual tool that is context dependent and shifts over time and space (Patterson et al. 2000). The reasons for dispersal, the nature of the relationship with the homeland and the host land, and differences *within* groups (such as class and gender) are all integral in shaping diasporic communities. The use of "African diaspora" emerged specifically in the 1950s in reference to shared experiences of those displaced by the Slave Trade, but is now commonly used to describe the contemporary global migrations of various African communities (Ibid.) who retain relationships with their homelands and an ethnonational identification whether that is Yoruba, Nigerian or African.

Related to diaspora, is the concept of *globalisation*. One reason for the surge of interest in diaspora has been the scale of movement of people fuelled by technological advances in transportation and media (Appadurai 1996). Whereas previous representations of space were based on notions of "break, rupture and disjunction" (Gupta et al. 1992), we now live in an era of "border crossings" where:

> "old-fashioned attempts to map the globe as a set of culture regions or homelands are bewildered by a dazzling array of postcolonial simulacra, doublings and redoublings, as India and Pakistan reappear in postcolonial simulation in London, prereveloution Tehran rises from the ashes in Los Angeles, and a thousand similar cultural dreams are played out in urban and rural settings all across the globe. In this culture-play of diaspora, familiar lines between "here" and "there", centre and periphery, colony and metropole are blurred."
>
> (Gupta et al. 1992: 10)

Notions of strictly bounded communities and geographical-cultural isomorphism no longer have purchase, superseded by ideas of deterratorialisation[33] and interconnectedness (Ibid.) that have challenged the supremacy of the nation-state (Appadurai 1996). However, this mass movement is not confined to people. Appadurai sees globalisation a product of global cultural flows in five domains that he terms *ethnoscapes, technoscapes, financescapes, mediascapes* and *ideoscapes* (Ibid.:

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[33] Appadurai describes this condition of the world we live in now as "rhizomic" (1996: 29) borrowing from the work of Deleuze and Guattari ([2004] 1980) who argue for the displacement of the defined, hierarchical structures of "arborescent" tree and root ontological models in favour of the *rhizome* which foregrounds connection and multiplicity: " unlike trees or their roots, the rhizome connects any point to any other point, and its traits are not necessarily linked to traits of the same nature" (Ibid.: 21). Appadurai uses the image of the rhizome to capture the interconnections, disjunctures and rootlessness of the contemporary globalised world. Also see Paul Gilroy's description of the "Black Atlantic" diaspora as a "rhizomorphic and fractal structure" (1993: 4)

33), pertaining to flows of people, technology, global capital, information (especially electronically) and ideologies respectively. Rather than being a homogenising force, globalisation has created *-scapes* in which cultural flows are characterised by disjuncture and "deeply perspectival" local articulations (Ibid.: 33). The work presented in this thesis draws upon the notion of transnational flows of culture to explore how African women are situated within a global interconnected space and how this impacts upon their management of HIV within the UK.

1.8.2 Structural violence

The concept of structural violence was developed by Johan Galtung in his seminal 1969 paper on peace and violence (Galtung 1969). For Galtung, violence extends beyond the physical domain and is "present when human beings are being influenced so that their actual somatic and mental realizations are below their potential realizations" (Ibid.: 168). He makes a distinction between "personal or direct" violence involving a subject who commits a violent act, and "structural or indirect" violence. Structural violence is not perpetrated by a subject but is instead "built into the structure and shows up as unequal power and consequently unequal life chances" (Ibid.: 171) as a result of the uneven distribution of resources and power, and is often not perceived directly. Galtung is careful to emphasise that "in both cases [either personal or structural violence] individuals may be killed or mutilated, hit or hurt in both senses of the words, and manipulated by means of carrot and stick strategies" (Ibid.: 170).

Structural violence is a central organising principle in Critical Medical Anthropology[34] with writers such as Philippe Bourgois[35] and Nancy Scheper-Hughes[36] focusing on how the macro-level forces of poverty, racism, gender inequality and political violence come to be embodied by people in the form of ill health. With specific reference to South Africa, Didier Fassin has explored how the legacy of Apartheid and the post-Apartheid economic and political situation have created conditions in which the HIV-pandemic has flourished, leaving its mark disproportionately on the most vulnerable in society (Fassin 2007). Paul Farmer in his work in Haiti, Russia, Rwanda and the United States has challenged the notion of individual risk behaviours, showing how increased

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[34] The branch of medical anthropology that uses critical theory and an explicit consideration of issues of power to explore the associations between social inequality and ill health.

[35] See Bourgois' work with crack dealers in East Harlem in which he traces the emergence of the crack cocaine economy subculture as "an alternative forum for autonomous personal dignity" in response to social marginalisation (1996).

[36] See Scheper-Hughes' study of high child mortality, and mothers' responses to infant death, in the context of chronic extreme poverty in a favela in North Eastern Brazil (1993).

vulnerability to HIV and poor access to HIV care are predominantly driven by poverty, lack of health infrastructure, unequal gender relations, discriminatory practices and aspects of national and international policy (Farmer 2004).

There is therefore a clear precedent for employing the concept of structural violence in the analysis of disparities in health, especially in work on HIV. In this thesis I explore how structural violence manifests itself particularly under conditions of diaspora in the UK and how it impacts on African women's utilisation of HIV services.

1.8.3 Stigma

The Oxford English Dictionary defines stigma as a mark of disgrace associated with a particular circumstance, quality or person" (2011). Its origins are in the Ancient Greek term referring specifically to bodily signs (such as incisions or branding) that were "designed to expose something unusual about the moral status of the signifier" (Goffman [1990] 1963: 11), although its common usage now extends beyond physical manifestations. Goffman views stigma as "a special discrepancy between virtual and actual social identity"[37] where someone possesses an "attribute that is deeply discrediting" (Ibid.: 13) leading to discrimination "through which we effectively, if often unthinkingly, reduce … life chances" (Ibid.: 15). For Goffman, stigma is profoundly relational and is located in the interactions between people, making a distinction between those whose stigmatising characteristic is evident or known about, the "discredited", and those whose difference is not apparent or known about, the "discreditable" (Ibid.: 14). The risk of the disclosure of the discreditable attribute is that it "spoils" social identity by revealing the discrepancy between virtual and actual identity (Ibid.: 31). The concealment of the discreditable attribute involves the careful management of information (Ibid.: 57) in order to "pass" as "normal" (Ibid.: 95), which has particular salience in the context of HIV and fears about disclosure of status.

Goffman's theory of stigma has been highly influential and is the dominant theoretical frame for much health research exploring the impact of stigma, including within HIV. Although it provides a useful framework for conceptualising stigma, its focus is on the micro-interactions between people. More recent work by Parker and Aggleton, with

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[37] Goffman uses the term "social identity" to describe the composite of structural and personal characteristics ascribed to people based on social categories, for example assumptions made on discovering someone's occupation. However, this identity is "virtual" in that it is imputed from normative expectations of a person belonging to that "category" of person and may be discrepant with an individual's true attributes, their "actual social identity" ([1990] 1963: 12).

specific reference to HIV and AIDS-related stigma and discrimination, places stigma within a wider context of structural forces, attending to issues of power and domination[38] and highlighting how the "strategic deployment" of stigma serves the interests of dominant groups (Parker et al. 2003). Furthermore, other forces of social inequality articulate closely and synergistically with stigma to produce vulnerability (Castro et al. 2005)[39]. I use Goffman's theory of stigma and this more recent work on the role of power and domination to explore the interpenetration of stigma and structural violence as experienced by migrant African women living with HIV in the UK.

1.9 Structure of this thesis

The thesis comprises eleven chapters, including this introductory chapter and six empirical chapters. Quantitative and qualitative data are integrated where possible.

In Chapter Two I locate my research question within existing knowledge of HIV and pregnancy in resource-rich settings. I present a narrative literature review specifically focusing on the five key clinical and service-related outcomes explored in this thesis, and a review of qualitative literature that explores pregnancy in the context of HIV in the UK.

In Chapter Three I describe the overall mixed methods approach I have used in this thesis. I provide an overview of the mixed-methods model I have adopted in this work, before describing in detail the specific methods and analytic approaches used in the quantitative and qualitative phases of this study.

In the first of my empirical chapters, Chapter Four, I draw upon NSHPC data to provide a broad epidemiological overview of pregnancy in HIV-positive African women living in the UK. I present data on trends over time in ethnicity of women, maternal African region of birth and duration of residence in the UK. I then present baseline demographic and clinical characteristics of women whose pregnancies form the basis of analyses in Chapters Five, Seven and Eight.

In Chapter Five, a mixed methods empirical chapter, I present the results of analyses of

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[38] This work is informed by critical theory with particular reference to Foucault's notion of the inherent issues of power in the social production of difference (Foucault 1978), Bourdieu's concept of *symbolic violence* as "the process by which symbolic systems (words, images, practices) promote the interests of dominant groups" (Parker et al. 2003: 18), and *hegemony* in which dominant groups secure their position over subordinate groups consensually via structuring fields of ideology and meaning (Gramsci 1970).

[39] The authors discuss how HIV-related stigma is often more pervasive in those experiencing poverty, gender inequality and racism and that the combined forces of social inequalities and stigma interpenetrate to constrain people's capacity to manage their illness further.

NSHPC data investigating the association between maternal ethnicity, region of birth and duration of residence in the UK and (i) uptake of ART, (ii) detectable viral load at delivery, and (iii) vertical transmission, in African women. I then draw upon ethnographic data to explore women's experiences of taking, or not taking, ART during pregnancy.

Pentecostal faith and beliefs in divine healing are often cited by professionals as a potential barrier to engagement with HIV care. In Chapter Six I explore the role of Pentecostalism in managing illness, with specific reference to HIV, drawing mainly upon ethnographic material collected during fieldwork in a diasporic African Pentecostal church in London. I situate illness within a broader cosmological framework of spiritual misfortune and explore factors that underpin the popularity of Pentecostalism among African migrants in order to challenge misconceptions about beliefs in divine healing as irrational. I conclude by considering whether it acts as a barrier to engagement with HIV services and interventions.

In Chapter Seven, I explore African women's engagement with and experiences of health services *during* pregnancy, using both quantitative and qualitative data. I present the results of my analyses of epidemiological data investigating the association between late antenatal booking and maternal ethnicity, region of birth and duration of residence in the UK. These epidemiological findings are contextualised with ethnographic data exploring women's attitudes towards and experiences of health services. I conclude by drawing upon ethnographic data to specifically explore women's experiences of maternity services at the time of delivery.

In Chapter Eight, the last of my mixed methods empirical chapters, I explore the engagement with HIV services by African women for their own care *after* pregnancy. I start by using NSHPC data to examine the association between loss to follow-up from HIV care after pregnancy and maternal ethnicity, region of birth and duration of residence in the UK. I then contextualise these findings with ethnographic data to explore why most women continue to engage with HIV services after pregnancy, and why other may find it harder to engage.

In Chapter Nine I present ethnographic data on infant-feeding decision making in HIV-positive African women. I describe the social context in which these decisions are made and the profound social impact of not breastfeeding on this group of women. I outline specific difficulties women experience in adhering to national guidelines to abstain from breastfeeding and trace an emergent resistance to these recommendations.

In Chapter Ten I present a synthesis of my quantitative and qualitative findings with reference to the overarching research question and the specific questions posed in this thesis. I highlight how my research has generated new knowledge in key areas and conclude with a discussion of the strengths and limitations of my methodological approach in this thesis.

In my final chapter (Chapter Eleven) I highlight the significance of my findings, specifically discussing implications for further work and making key recommendations for the collection of surveillance data, the delivery of clinical services, and the development of wider public policy.

2

Literature Review

Summary

In this chapter I present a literature review specifically focusing on HIV and pregnancy and the five key clinical and service-related outcomes explored in this thesis. These are (i) uptake of ART in pregnancy, (ii) maternal HIV viral load at delivery, (iii) vertical transmission of HIV, (iv) timing of antenatal booking among HIV-positive women, and (v) loss to follow-up after pregnancy. I also present a narrative review of qualitative literature that explores pregnancy in the context of HIV in the UK.

2.1 Introduction

The overarching question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? This thesis explores key clinical and service-related outcomes, and their association with maternal ethnicity, African region of birth and maternal duration of residence in the UK; as well as women's experiences during and after pregnancy. In this chapter I locate my work within existing knowledge of HIV and pregnancy in resource-rich settings[40]. I present a narrative literature review[41] specifically focusing on HIV and pregnancy and the five key clinical and service-related outcomes explored in this thesis. These are (i) uptake of ART in pregnancy, (ii) maternal HIV viral load at delivery, (iii) vertical transmission of HIV, (iv) timing of antenatal booking among HIV-positive women, and (v) loss to follow-up after pregnancy. I also present a narrative review of qualitative literature that explores pregnancy in the context of HIV in the UK.

2.2 Uptake of antiretroviral therapy in pregnancy

The advent of antiretroviral therapy, most importantly HAART, has resulted in dramatic declines in deaths and diagnoses of AIDS (Health Protection Agency 2012), as well the prevention of other comorbidity such as cardiovascular disease (Emery et al. 2008).

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[40] Studies in resource-poor settings predominate in the field of HIV and pregnancy however findings from these studies are rarely generalisable to resource-rich settings such as the UK.

[41] See Appendix iii for the search strategy used for this review. A systematic review of work on HIV and pregnancy was beyond the scope of this thesis.

Uptake of ART in the general HIV-positive population with CD4 counts below the treatment threshold (<350 cells/mm^3) has recently been estimated at just over 90% in a clinic population in the UK (Kober et al. 2011). In the same study, a lower CD4 count and a higher viral load were predictive of taking ART (Ibid.). Risk factors for *not* taking ART include younger age (Kober et al. 2011, Fleishman et al. 2012a), not being at an advanced stage of disease (Ezzy et al. 1998) and injecting drug use (Kober et al. 2011). Evidence for the effect of gender is conflicting with some studies finding that women are less likely to take ART than men (Ezzy et al. 1998, Fleishman et al. 2012a), whilst others finding that female gender is associated with increased uptake (Kober et al. 2011). Similarly, there is no consensus on the effects of race and/or ethnicity. A systematic review of twenty-six studies between 1984 and 1999 concluded that there was evidence of racial and/or ethnic disparities in uptake of ART (Palacio et al. 2002) with recent work from the United States also finding that decreased uptake was associated with Black race (Fleishman et al. 2012a). Studies from the UK and Italy have found no association between uptake and ethnicity (Elford et al. 2008b), and being a migrant (Floridia et al. 2007) respectively.

ART is the mainstay of prevention of vertical transmission and the use of ART by HIV-positive pregnant women in resource-rich settings is high[42], having increased over time (Lansky et al. 1999, Giles et al. 2008, Townsend et al. 2008b, Bailey et al. 2011, Townsend et al. 2013). In the UK, 99% of women diagnosed with HIV received ART during pregnancy between 2007 and 2011 (Townsend et al. 2013) with comparably high rates of uptake in other parts of Europe (Mayaux et al. 2003, Bailey et al. 2011). Studies have identified similar risk factors for non-uptake of ART among pregnant women and non-pregnant HIV-infected population. These include asymptomatic disease (Bailey et al. 2011) and substance misuse (Abatemarco et al. 2008, Bailey et al. 2011, Elenga et al. 2012). Risk factors specific to pregnancy include being diagnosed with HIV late in pregnancy (Mayaux et al. 2003), suboptimal antenatal care (Lansky et al. 1999, Mayaux et al. 2003, Abatemarco et al. 2008), preterm delivery (Mayaux et al. 2003) and lack of partner support of ART use (Kiarie et al. 2003). Again, the role of race and/or ethnicity remains unclear with a study in the US reporting decreased uptake in pregnant Black women (Abatemarco et al. 2008) but no disparities in uptake according to ethnic group identified within a French cohort of pregnant women

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[42] It is important to note that uptake of ART during pregnancy is also high in low and middle-income countries although this is not the focus of my thesis (Ekama, et al. 2012, Kinuthia, et al. 2011, Kreitchmann, et al. 2012).

(Mayaux et al. 2003).

A recent analysis of UK and Ireland data from the NSHPC between 2005 and 2010 looked specifically at women who received less than fourteen days of ART prior to delivery[43] and found that this group had high rates of vertical transmission at 13% (Modestini et al. 2012). The main predictor of sub-optimal ART was being diagnosed with HIV during pregnancy. The authors found no association with being born in Africa; they did not look further at differences among African women. Follow-up questionnaires sent to participating clinics identified late antenatal booking, denial of HIV status, and refusal of treatment by women as important explanatory factors. In that study eleven women were documented not to have received ART during pregnancy, of whom six had been diagnosed at term. The work presented in this thesis includes *all* eligible pregnancies over a longer time period and is therefore larger in scale. Furthermore, it specifically focuses upon the association between not receiving any ART during pregnancy and maternal ethnicity, African region of origin and duration of residence in the UK.

2.3 Detectable maternal HIV viral load at delivery

Maternal HIV viral load at delivery is the most important predictor of vertical transmission of HIV (Garcia et al. 1999, European Collaborative Study 2005, Townsend et al. 2008a) and control of this is the main mechanism by which ART prevents transmission of HIV to the infant (Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission 2012). Pregnancy does not appear to affect women's response to ART (Rachas et al. 2013). Lack of virological suppression may indicate sub-optimal response to ART or poor adherence and may result in the development of resistant virus[44], compromising a woman's future ART treatment options. In a previous analysis based on combined data from the NSHPC and the European Collaborative Study (ECS) between 2000 and 2009, I reported that maternal HIV viral load was detectable at delivery in 25% of pregnancies reported in HIV-positive women (Tariq et al. 2011). This is comparable to rates of between 19% and 35% reported in other studies from Europe, the United States and Brazil (Patel et al. 2007, Baroncelli et al. 2009, Katz et al. 2010, Joao et al. 2012, Rachas et al. 2013).

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[43] This study included data from the NSHPC and data from questionnaires sent to NHS HIV antenatal clinics. Approximately 25% of eligible pregnancies were excluded from this study due to non-response from clinics for further data.

[44] HIV drug resistance is the ability of the HIV virus to replicate and mutate in the presence of antiretroviral drugs that can lead to failure of certain drug regimens.

High maternal HIV viral load early in pregnancy is one of the most important predictors of detectable viral load at delivery (Louis et al. 2005, Patel et al. 2007, Floridia et al. 2010, Joao et al. 2012, Kay et al. 2012, Read et al. 2012), as is duration of ART (Joao et al. 2012, Read et al. 2012, Rachas et al. 2013). The class of ART used in pregnancy may play a role with nevirapine-based[45] regimes having been shown to result in faster rates of viral suppression (Patel et al. 2007, Kay et al. 2012). There is also evidence that a non-nucleoside reverse transcriptase inhibitor[46] regime (NNRTI) in a previous pregnancy increases the risk of not adequately suppressing the virus (French et al. 2013) Other risk factors for detectable viral load at delivery include substance misuse (Katz et al. 2010), change in ART regime during pregnancy (Floridia et al. 2010) and preterm delivery (O'Shea et al. 1998). The few studies that have explored behavioural risk factors for detectable viral load at delivery have found associations with poor adherence to ART (Louis et al. 2005, Weinberg et al. 2009) and non-disclosure to partners (Jasseron et al. 2011).

Very few studies have looked at the effects of ethnicity on maternal viral load at delivery. Two studies, both from Italy, found that migrant women (mainly African) did not have an increased risk of detectable viral load at delivery (Floridia et al. 2007, Izzo et al. 2011). Patel et al (2007), in their analysis of ECS data, also found no association between ethnicity and detectable viral load at delivery, although they demonstrated faster rates of virological suppression in West African women which they hypothesise may be due to differences in maternal HIV subtype or host biological factors. The work presented in this thesis is the first study in the UK to explore the association between ethnicity and maternal viral load at delivery. It is also the first study anywhere, to the best of my knowledge, to specifically look at differences in virological response among pregnant HIV-positive African women according to region of birth and duration of residence in the host country.

2.4 Vertical transmission of HIV

Transmission of HIV from a mother to her infant can occur before or during delivery, or after delivery through breastfeeding[47] (Newell 1998). In the absence of medical

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[45] An antiretroviral medication that is commonly used during pregnancy worldwide.

[46] One of the five classes of antiretroviral medications currently licensed for the treatment of HIV. This class includes the commonly used drug in pregnancy nevirapine.

[47] The overwhelming majority of cases of vertical transmission in the UK in women diagnosed with HIV will be as a result of in-utero or perinatal transmission as breastfeeding is rare in this setting (see Chapter Nine).

interventions the rate of vertical transmission has been estimated to be between 25% and 40% (Newell et al. 1997). With appropriate medical management the rate of transmission can be reduced to less than 2% (Warszawski et al. 2008, Baroncelli et al. 2009, European Collaborative Study 2010, von Linstow et al. 2010). Overall in women diagnosed with HIV by the time of delivery, the vertical transmission rate in the UK between 2007 and 2011 was 0.57%, reaching 0.46% in 2010 (Townsend et al. 2013), a dramatic decline from a peak of nearly 20% in 1993 (Duong et al. 1999). The majority of cases of perinatal transmission now occur in women who have had less than two weeks of ART or none at all (Modestini et al. 2012), many of these being women diagnosed with HIV during labour or after delivery (National Study of HIV in Pregnancy and Childhood (NSHPC) et al. 2007).

Duration of ART is an important determinant of vertical transmission with longer duration of ART associated with lower risk of transmission (Bailey et al. 2011, Forbes et al. 2012, Townsend et al. 2013). This is reflected by vertical transmission rates as low as 0.19% in women conceiving on ART (Townsend et al. 2013). As highlighted in the previous section, maternal HIV viral load plays a pivotal role in vertical transmission. Recent NSHPC data has highlighted the negligible rate of transmission (0.05%) when a woman has a viral load close to delivery of <50 copies/ml (Townsend et al. 2013). Elective caesarean section has also long been an important component in the prevention of vertical transmission (Kind et al. 1998, European mode of delivery collaboration 1999, International Perinatal HIV Group 1999). However recent data demonstrating rates of vertical transmission of less than 0.5% regardless of mode of delivery have led to a shift in practice to planned vaginal delivery in women who are virologically suppressed (Boer et al. 2007, Townsend et al. 2008a, Warszawski et al. 2008, Boer et al. 2010)

Obstetric factors that may increase the risk of vertical transmission, especially in the presence of circulating maternal virus, include premature rupture of membranes (Landesman et al. 1996, Kuhn et al. 1999, Tomarken 2001, Garcia-Tejedor et al. 2009), and invasive monitoring and other interventions (European Collaborative Study 1992, Kind et al. 1998, Garcia-Tejedor et al. 2009). Several infant-related factors have also been associated with an increased risk of HIV transmission including preterm delivery (European Collaborative Study 1992, Kuhn et al. 1999, Struik et al. 2008), low birthweight (Landesman et al. 1996, Garcia-Tejedor et al. 2009), twin pregnancy (Scavalli et al. 2007) and female sex (Piwoz et al. 2006, Brahmbhatt et al. 2009).

Maternal risk factors for vertical transmission identified in the literature include maternal seroconversion during pregnancy (Struik et al. 2008), low maternal CD4 count at delivery (Landesman et al. 1996, Ioannidis et al. 2001, European Collaborative Study 2005, Garcia-Tejedor et al. 2009), certain viral subtypes (Renjifo et al. 2001), coexistent infections (Mwapasa et al. 2006, Gupta et al. 2011), substance misuse (Landesman et al. 1996, Peters et al. 2008), non-HAART regimens (Siegfried et al. 2011) and treatment interruption during pregnancy (Martino et al. 2009). With regards to ethnicity and/or race, studies from France and the UK have not demonstrated an association between maternal ethnicity and vertical transmission (Jasseron et al. 2008, Townsend et al. 2008a), whilst increased transmission was seen in White women compared to Black and Hispanic women in a New York cohort (Peters et al. 2008). There have been no studies to date that have examined the effects of African region of birth or duration of residence in the host country on the risk of vertical transmission.

2.5 Late antenatal booking[48]

Antenatal care plays an important role in maternal and infant health (Bergsjø et al. 1997), providing a woman with information and support to make decisions about her pregnancy . Guidelines from both the UK and Ireland state that all women should have their first antenatal care appointment, known as "antenatal booking", by ten to thirteen weeks' gestation (National Institute for Health and Clinical Excellence 2008, Department of Health 2009). In 2010-2011, it was estimated that just over 30% of women in England had their booking appointment at thirteen weeks' gestation or beyond[49].

Low maternal socioeconomic status (Brown 1989, Essex et al. 1992, Melnikow et al. 1993, Beeckman et al. 2010), young maternal age (Essex et al. 1992, Blondel et al. 1998, Delvaux et al. 2001), not having a stable partner (Delvaux et al. 2001) and multiparity (Essex et al. 1992, Blondel et al. 1998) have all been identified as risk factors for late booking in studies from the United States and Europe. Studies specifically from the UK have identified similar risk factors (Simpson et al. 1980, Lewis 1982, Florey et al. 1994, Kupek et al. 2002, Rowe et al. 2008, Redshaw et al. 2010).

Maternal non-white ethnicity and migrant status have been shown to play an important role in late presentation to antenatal care. Studies in England have demonstrated an

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[48] Some of this material appears in Tariq et al 2012a .

[49] See NHS Maternity Statistics for 2010-2011 (provider level analysis tables) available at http://www.hscic.gov.uk/pubs/maternity1011 (accessed 23 September 2013).

association between late antenatal booking and black ethnicity (Rowe et al. 2008, Redshaw et al. 2010), and both being from a minority ethnic group and having been born outside of the UK (Redshaw et al. 2010). Immigration status is a further associated factor with a study from Switzerland reporting an eleven-fold higher risk of delayed prenatal care in undocumented migrant mothers compared with mothers with legal residency (Wolff et al. 2008). Similar associations between ethnicity or migrant status, and late booking have been reported in numerous other studies from the UK and elsewhere (Simpson et al. 1980, Chisholm 1989, Petitti et al. 1990, Essex et al. 1992, Melnikow et al. 1993, Delvaux et al. 2001, Kupek et al. 2002, Alderliesten et al. 2007, Park et al. 2007, Beeckman et al. 2010, Chote et al. 2011, Korinek et al. 2011). A systematic review of quantitative and qualitative literature on the use of antenatal care by "non-Western" women in industrialised Western countries has identified poor knowledge of healthcare systems, language difficulties, previous poor experience of healthcare, institutional barriers, lack of social support and recent migration as important explanatory factors (Boerleider et al. 2013)

Late initiation of antenatal care is associated with poor maternal and infant outcomes (Quick et al. 1981, Florey et al. 1994, Van Hanegem et al. 2011). A report from the UK's Confidential Enquiry into Maternal and Child Health (CEMACH) found that antenatal booking beyond twelve weeks gestation was more common in women whose pregnancies had resulted in a stillbirth or neonatal death (2009)[50]. Late booking may carry even greater risks in the context of HIV infection as effective prevention of vertical transmission is dependent upon early screening for maternal HIV infection, prompt initiation of ART, planning of infant delivery and timely support for women in making decisions about feeding their infant. There are few data on the presentation to antenatal care of women living with HIV. A small study from London found that a greater proportion of women living with HIV presented late to antenatal care compared with the local general obstetric population (Parisaei et al. 2007). One of the few studies exploring ethnicity and antenatal care in women living with HIV revealed that African migrants living in France were more likely to initiate antenatal care late than French-born women (Jasseron et al. 2008). In terms of HIV-related outcomes, suboptimal antenatal care[51] has been found to be associated with a decreased uptake of ART

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[50] It is important not to assume a causal link as women with socio-demographic risk factors for poor maternal and child health outcomes are also probably more likely to present late for care during pregnancy.

[51] Either late booking or fewer visits, or both.

(Lansky et al. 1999, Mayaux et al. 2003, Abatemarco et al. 2008) and an increased risk of both detectable viral load at delivery and vertical transmission (Wilson et al. 2004, Denoeud-Ndam et al. 2013). There have been no previous studies in the UK specifically investigating antenatal care access in women with HIV, and very few studies internationally exploring the association between initiation of antenatal care and maternal ethnicity, region of birth and duration of residence in the host country, in women living with HIV.

2.6 Loss to follow-up after pregnancy in women living with HIV

Current standards of care for people living with HIV issued by the British HIV Association state that >95% of people known to have HIV should have accessed clinical services within the past twelve months (British HIV Association 2012). Regular attendance for HIV care is important as it allows for monitoring of HIV and treatment-related side effects, provision of ART, access to reproductive and sexual health care, and provision of psychological and social support.

A national study of loss to follow-up[52] among adults attending HIV services in England, Wales and Northern Ireland between 1998 and 2006 found that 10% of adults attending for care in one year failed to attend in the following year (Rice et al. 2011); 5% never returned, a further 4% attended at some point later and less than 2% had died (Ibid.). A smaller study of patients attending a London clinic between 1997 and 2005 found that one in five of their patients never returned for HIV care (Gerver et al. 2010). However, both of these studies were limited by lack of information on emigration. A recent audit of adults in England, Wales and Northern Ireland with diagnosed HIV found that of 2255 patients who did not access care in 2011[53], one in four had left the UK (Clay 2013). Taking into account emigration, reporting errors and death, the authors estimate that at most 2.6% of people with diagnosed HIV who remained in the UK did not access care in 2011 (Ibid.). Factors associated with disengagement from care include female gender, younger age, recently diagnosed HIV and not being on ART (Gerver et al. 2010, Rice at al. 2011, Clay 2013). Clay (2013) also identifies stigma, poverty and women’s responsibilities as sole carers for children as important barriers to accessing ongoing HIV care. A consistent finding across UK studies is the association between black

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[52] There is no consensus in the literature on how to define loss to follow-up, which makes it difficult to compare across studies. Broadly, loss to follow-up is a measure of how many patients fail to maintain engagement with HIV care. A range of measures are used across studies based mainly based on either varying periods of time since last clinic visit or number of visits over a defined period.

[53] This audit was based on those who were known to have accessed care in 2010.

African ethnicity and loss to follow-up ART (Gerver et al. 2010, Rice at al. 2011, Clay 2013). The association between poorer retention in HIV care and non-White ethnicity and/or race has also been reported in studies from other parts of Europe and the United States (Fleishman et al. 2012b, Hall et al. 2012, Helleberg et al. 2012, Thierfelder et al. 2012, Rebeiro et al. 2013).

HIV antenatal and PMTCT (prevention of mother-to-child transmission) programmes offer an opportunity to engage women in long-term HIV care. However, pregnant women and new mothers share many of the risk factors identified above as barriers to engagement in care. Few studies have explored loss to follow-up after pregnancy in women living with HIV. The majority have been conducted in resource-poor settings, revealing rates of attrition of between 20% and 83% (Panditrao et al. 2011, Ferguson et al. 2012, Clouse et al. 2013). Factors associated with disengagement with care after pregnancy include late antenatal booking (Panditrao et al. 2011), institutional barriers (Ferguson et al. 2012), lower educational level (Panditrao et al. 2011), poverty (Panditrao et al. 2011), not being on ART (Coria et al. 2012), concerns about HIV disclosure and stigma (Bwirire et al. 2008, Chinkonde et al. 2009), and lack of support especially from partners (Bwirire et al. 2008, Chinkonde et al. 2009, Gilles et al. 2011). Data from resource-rich settings are extremely limited. Among a cohort of HIV-positive women in Paris, a quarter did not attend for their own HIV care two years after delivery of their child, although they did return for appointments for their child (Lemly et al. 2007). The only study that has looked at postnatal loss to follow-up in the context of HIV in the UK is an audit of thirty-nine women in a North London hospital showing that 65% of women did not access HIV care within three months post-partum (Saulsbury et al. 2004). Recent data from the NSHPC has revealed that two fifths of women with a second pregnancy reported to the NSHPC had presented with a low CD4 count in that pregnancy, with 5% presenting with symptomatic HIV or AIDS (French et al. 2012), suggesting sub-optimal HIV follow-up after pregnancy in a proportion of HIV-positive women.

2.7 Experiences of pregnancy in HIV-positive women in the UK

There is a paucity of qualitative research exploring pregnancy in the context of HIV infection in the UK, with the majority of existing studies originating in either Sub-

Saharan Africa[54] or the United States[55]. Only six studies have explored pregnancy and/or motherhood in the context of HIV in the UK (see table 2.1). These studies were conducted in a variety of settings and vary in their methodological approaches and theoretical frames. Only two studies specifically focus on migrant African women living in the UK (Doyal et al. 2005, Treisman et al. 2013), and only two explore HIV-positive women's experiences of health services during pregnancy (Naftalin et al. 2010, Kelly et al. 2012b).

A landmark 2005 study conducted with HIV-positive African women (many of whom were mothers), revealed the exigencies of everyday life as a migrant African woman living with HIV in London with poverty and poor housing very common (Doyal et al. 2005). Those without residency status in the UK also faced the pervasive fear of deportation and the frustration of not being able to travel back to their home countries to visit family. Almost all the women in this study described fear of disclosure of their HIV-status, resulting in a restriction of social interaction including their ability to engage with support services. Health services are therefore a centrally important resource for migrant women living with HIV, not only providing medical care but also addressing social and psychological needs.

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[54] For example see Cooper at al's work from South African on reproductive decision-making among HIV-positive men and women in South Africa which highlights the importance of parenthood, especially motherhood, in conforming to hegemonic gender identities (2007). Carol Long's monograph on HIV-positive motherhood in South African is also important, emphasising the experiences of disruption and dissonance in the context of HIV-positive motherhood and women's overwhelming fear for the health of their children (2009).

[55] Key references from the US emphasise the strong desire for motherhood in the context of HIV, and the role of parenthood in providing meaning (D'Auria, et al. 2006, Kirshenbaum, et al. 2004). See also Sandelowski's (2003) metasynthesis of qualitative findings on HIV and motherhood, which highlight the "work" involved in protecting children from HIV infection and preserving a positive maternal identity.

Table 2.1: Summary of qualitative studies on HIV and pregnancy in the UK

Authors	Focus of study	Recruitment	Number of participants	Participant characteristics	Methods
Doyal and Anderson (2005)*	How migrant African HIV positive women's lives are shaped by gender, migration and seropositivity	Women attending NHS HIV services in London	62	All Sub-Saharan Black African; diagnosed HIV>6 months; not necessarily pregnant	Questionnaire and semi-structured interviews using life history approach
Wilson (2007)	The interplay between identity and illness in HIV-positive mothers	Women attending voluntary organisations in Scotland	12	All White British/European, diagnosed HIV<1995; six with history of injecting drug use	Semi-structured interview using grounded theory and narrative approach
Carter (unpublished MSc thesis, 2009)	The social impact of HIV in pregnancy	Women attending HIV support organisations in London	7	Six Sub-Saharan African; previous pregnancy since diagnosis	Open-ended interview with content analysis
Naftalin, Moore et al. (2010)	How HIV influences decisions regarding conception and pregnancy	Women attending NHS HIV services in South East England	8	Five Sub-Saharan African; currently pregnant or previous pregnancy since HIV diagnosis,	Semi-structured interviews with thematic analysis
Kelly, Alderdice et al. (2012a, 2012b)	Reproductive decision-making and experience of pregnancy and childbirth following HIV diagnosis	HIV-affected women and men attending regional HIV unit in Northern Ireland	15	Combination of Sub-Saharan African, Asian and Caucasian; HIV-positive or partners of people living with HIV; trying to conceive or pregnant	Unstructured interviews using a narrative approach
Treisman, Jones et al. (2013)	How UK-based African women perceive, make sense of, and manage an HIV diagnosis during pregnancy and after delivery	Women who had attended or were attending an antenatal support group in London for HIV-positive African women	12	African, experience of being diagnosed with HIV during pregnancy	Semi-structured interviews with interpretative phenomenological analysis (IPA) approach

*****This study is included as although its focus was not specifically pregnancy, motherhood emerges as a central theme.

The centrality of motherhood in constructing female identity and achieving normality is emphasised in many studies (Doyal et al. 2005, Naftalin et al. 2010, Kelly et al. 2012b). Motherhood provides an important reason to live (Doyal et al. 2005, Wilson 2007, Naftalin et al. 2010, Kelly et al. 2012a) but is disrupted in the context of HIV (Kelly et al. 2012a), with women experiencing themselves as a potential source of danger to their children (Wilson 2007, Kelly et al. 2012a). Widespread and deep-rooted anxieties about vertical transmission of HIV (Naftalin et al. 2010, Kelly et al. 2012a) result in women being highly motivated to take ART and engaging well with care, many finding solace in medical interventions that reduce the risk of transmission to their babies (Naftalin et al. 2010, Kelly et al. 2012b). However, women often find the interventions difficult (Naftalin et al. 2010) with the avoidance of breastfeeding identified as particularly challenging due to the cultural importance of breastfeeding and fears about bonding (Treisman et al. 2013). Fear and experiences of stigma predominate in these studies with women often anxious about disclosing to support networks, resulting in careful management of information (Carter 2009, Kelly et al. 2012b) and social isolation (Carter 2009). Healthcare providers therefore become an important source of support (Naftalin et al. 2010, Kelly et al. 2012b), with continuity of care with a specialist team highly valued (Kelly et al. 2012b). However, this trust in healthcare systems can be compromised by negative experiences such as lack of compassion, poor knowledge and discriminatory attitudes from key professionals (Wilson 2007, Kelly et al. 2012b).

Key qualitative and theoretical texts that inform the qualitative analyses in this thesis are presented in the relevant chapters (Five to Nine), as is the convention in ethnographic writing, in order to create a dialogue between my findings and existing work.

2.8 Conclusions

Little is known both internationally and within the UK on key service-related outcomes among pregnant women living with HIV such as initiation of antenatal care and loss to follow-up after pregnancy. Furthermore, the impact of ethnicity, and the potential heterogeneity within broad ethnic groups, has been relatively overlooked when exploring both key clinical and service-related outcomes including uptake of ART during pregnancy, maternal viral load at delivery and antenatal booking.

Only six qualitative studies to date have engaged with experiences of pregnancy and motherhood among women living with HIV in the UK (see table 2.1). Only two of these focused upon African migrant women (Doyal et al. 2005, Treisman et al. 2013), and only one of these specifically explored pregnancy (Treisman et al. 2013). The degree of analytic depth and theoretical engagement varies across these six studies and one of them remains unpublished. None of these studies take an ethnographic approach and all are based exclusively on some variation of interviews. Furthermore there is no explicit focus in these studies on macro-level factors such as poverty and public policy, which are likely to constrain women's agency when seeking care and are often overlooked (Hampanda 2012)[56].

The work presented in this thesis attempts to bridge this gap in existing knowledge on HIV and pregnancy by exploring maternal outcomes in African women and their association with ethnicity, region of birth and duration of residence in the UK. The epidemiological findings are contextualised with ethnographic research exploring women's experiences during and after pregnancy, with a particular focus on the broader structural factors that may constrain women's engagement with HIV care. The combination of both quantitative *and* qualitative methods in a single study to explore pregnancy in HIV-positive women has not been undertaken before, presenting an opportunity to gain new knowledge and to explore methodological boundaries.

Key points

- There are few studies internationally, and none from the UK, that explore antenatal booking and loss to follow-up after pregnancy in HIV-positive women.

- Data on the impact of ethnicity, region of birth and maternal duration of residence on outcomes on clinical and service-related outcomes in pregnancy are lacking.

- There are very few qualitative studies that engage with the lived experience of pregnancy and motherhood in HIV-positive women in the UK, especially among African women who are the largest group.

- There is a paucity of literature pertaining to HIV and pregnancy that explores the impact of structural factors on women's engagement with HIV care.

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[56] Hampanda notes in her review of literature on the prevention of vertical transmission (2012) that the majority of studies to date have focused on individual level constructs, such as psychological models of health beliefs and behaviour, to the exclusion of a theoretical engagement with structural inequalities such as gender and poverty.

3

Methods

Summary

In this chapter I describe the overall mixed methods approach I have used in this thesis. I start by introducing mixed-methods research as a methodological[57] approach, moving on to describe the mixed-methods model I have adopted in my work. I then describe in detail the specific methods and analytic approaches [58]used in the quantitative and qualitative phases of this study[59].

3.1 Mixing methods

In the previous chapter I situated this thesis within existing knowledge on HIV and pregnancy, particularly focusing on literature pertaining to migrant women and women from minority ethnic communities. This narrative review encompassed literature from both quantitative and qualitative research traditions, highlighting the role both approaches play in understanding the complex role of ethnicity and migration in pregnancy in HIV-positive women. The narrative review sets the stage for this chapter in which I describe the overall mixed methods approach I have used in this thesis.

The overarching research question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? The three specific questions posed are:

1. Are maternal ethnicity, African region of birth and duration of residence in the UK *associated* with:
    a. Not receiving ART during pregnancy
    b. Detectable maternal HIV viral load at delivery

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[57] I use the term *methodology* to describe the body of practices, the underlying philosophy and the fundamental assumptions of a research approach. I use *methods* to describe the specific techniques deployed to collect and analyse data.

[58] Some of this material appears in Tariq, et al. 2012b .

[59] I will describe the quantitative methods before the qualitative methods. This is a reflection of the chronological structure of my research rather than an indication of priority of methods. The quantitative and qualitative aspects of the study both carry equal weight in the overall thesis.

   c. Vertical transmission of HIV

   d. Late antenatal booking

   e. Loss to follow-up from HIV care in the year after pregnancy

2. What are the *mechanisms* underlying associations between clinical and service outcomes, and maternal ethnicity, African region of birth and duration of residence in the UK?

3. What are the experiences of African women living with HIV during and after pregnancy?

Understanding engagement with care during and after pregnancy involves exploring clinical outcomes; access to services; beliefs about illness, health and childbearing; and lived experiences. The complex and multidimensional nature of the phenomena studied disrupts a simple dichotomy of quantitative and qualitative methodologies. Instead, I have deployed a *mixed methods* approach, using quantitative and qualitative methods to answer the specific questions posed in this thesis in order to gain a breadth and depth of understanding African women's engagement with HIV services and interventions during and after pregnancy.

3.1.1 Mixed methods as a methodological paradigm[60]

The most widely accepted definition of mixed methods research, and the one that I use in this thesis, is research that "focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or a series of studies" (Creswell et al. 2007: 5). Mixed methods research is a broad umbrella term for a wide spectrum of study designs which vary in terms of methodological priority (the emphasis placed on each method) and the sequence in which methods are deployed (Creswell et al. 2007)[61]. The central premise of mixed methods research is "that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone" (Creswell et al. 2007: 5).

There has been extensive debate on the validity of mixed methods as a methodological

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[60] Some of this material appears in Tariq, et al. 2013.

[61] Quantitative and qualitative methods can be deployed sequentially or concurrently, and the level of integration between the approaches within a single study can vary greatly.

approach. Drawing upon Thomas Kuhn's notion of paradigms ([1996] 1962) [62], methodological purists believe that quantitative and qualitative methodologies cannot be combined as they are founded upon fundamentally conflicting ontologies and epistemologies. This rigid enforcement of paradigmatic boundaries has been countered by the mixed methods research community with a number of arguments[63]. In the past twenty years, mixed methods has emerged as a distinct methodology in its own right with the development of its own notation system (Morse 1991) and a description of typologies (Greene et al. 1997). The establishment of a major international conference of mixed methods research, the publication of key textbooks (Tashakkori et al. 2003, Creswell et al. 2007) and the launch of the Journal of Mixed Methods Research in 2007, have been instrumental in the growing visibility of mixed methods approaches. The increasing recognition and acceptance of mixed methods by researchers within health-related fields is reflected by the growing numbers of published studies that use this approach (O'Cathain et al. 2007). Mixed methods research is now accepted as an innovative and useful approach in addressing complex questions and meeting the demands for sophisticated evidence in health research.

Quantitative research is traditionally associated with a positivist stance and a belief that reality can be measured and observed objectively. Most commonly, it sets out to test an *a priori* hypothesis and is therefore conventionally described as deductive. Strengths of quantitative research include its procedures to minimise confounding and its potential to generate generalisable findings if based on samples that are both large enough and representative. It remains the dominant paradigm in health research. However this deductive approach is less suited to generating hypotheses about how or why things are happening, or explaining complex social or cultural phenomena.

Qualitative research most often comes from an interpretive framework and is usually informed by the belief that there are multiple realities shaped by personal viewpoints, context and meaning. Qualitative approaches are usually described as inductive as questions are often open-ended with the analysis allowing hypotheses to emerge from

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[62] Kuhn's notion of paradigms is the set of practices and foundational beliefs held by a disciplinary community at a point in time, which are fundamentally incommensurable with others.

[63] Many mixed methods researchers have drawn from the American philosophical tradition of pragmatism arguing that for a move beyond paradigm boundaries towards an assessment of methodological approaches based on their capacity to successfully address a research question. On the other hand some mixed methods researchers embrace the differences inherent in methodological paradigms, using them dialectically and seeing the tensions as potential spaces to generate insight (Greene, et al. 1997). Others argue that the boundaries drawn between qualitative and quantitative approaches are arbitrary and exaggerated, stating that both seek to generate data to describe and address questions, and that both approaches have inherent biases that they seek to minimise (Paley, et al. 2011).

data. Qualitative research can generate robust theory that is applicable to contexts outside of the study area in question, helping to guide practitioners and policy-makers (Murphy et al. 1998). However, for research that aims to directly impact on policy and practice, the findings of qualitative research can be limited by the small samples sizes that are necessary for in-depth exploratory work and the consequent lack of generalisabilty.

Mixed methods research therefore has the potential to harness the strengths and counterbalance the limitations of each approach and can be especially powerful when addressing multifaceted questions such as those posed in this thesis.

3.1.2 Mixed methods in the context of this PhD

As discussed earlier in this chapter, this thesis seeks to explore the complex, multidimensional nature of engagement with HIV care during and after pregnancy among African women living with HIV in the UK. The three specific research questions encompass clinical outcomes, access to services, and beliefs and experiences, necessitating a mixed methods approach.

In this thesis I combine epidemiological and anthropological methods. I have used a sequential explanatory model with a quantitative phase followed by a qualitative phase (Tashakkori et al. 2003, Creswell et al. 2007)[64]. My overall study design is summarised in figure 3.1 and a Gantt chart of the quantitative and qualitative components is presented in table 3.1. The first phase was quantitative, comprising analysis of national surveillance data. This was followed by a qualitative phase which sought to explain and contextualise the findings from the first phase whilst highlighting other important aspects of women's experience. This qualitative phase comprised semi-structured interviews and participant observation.

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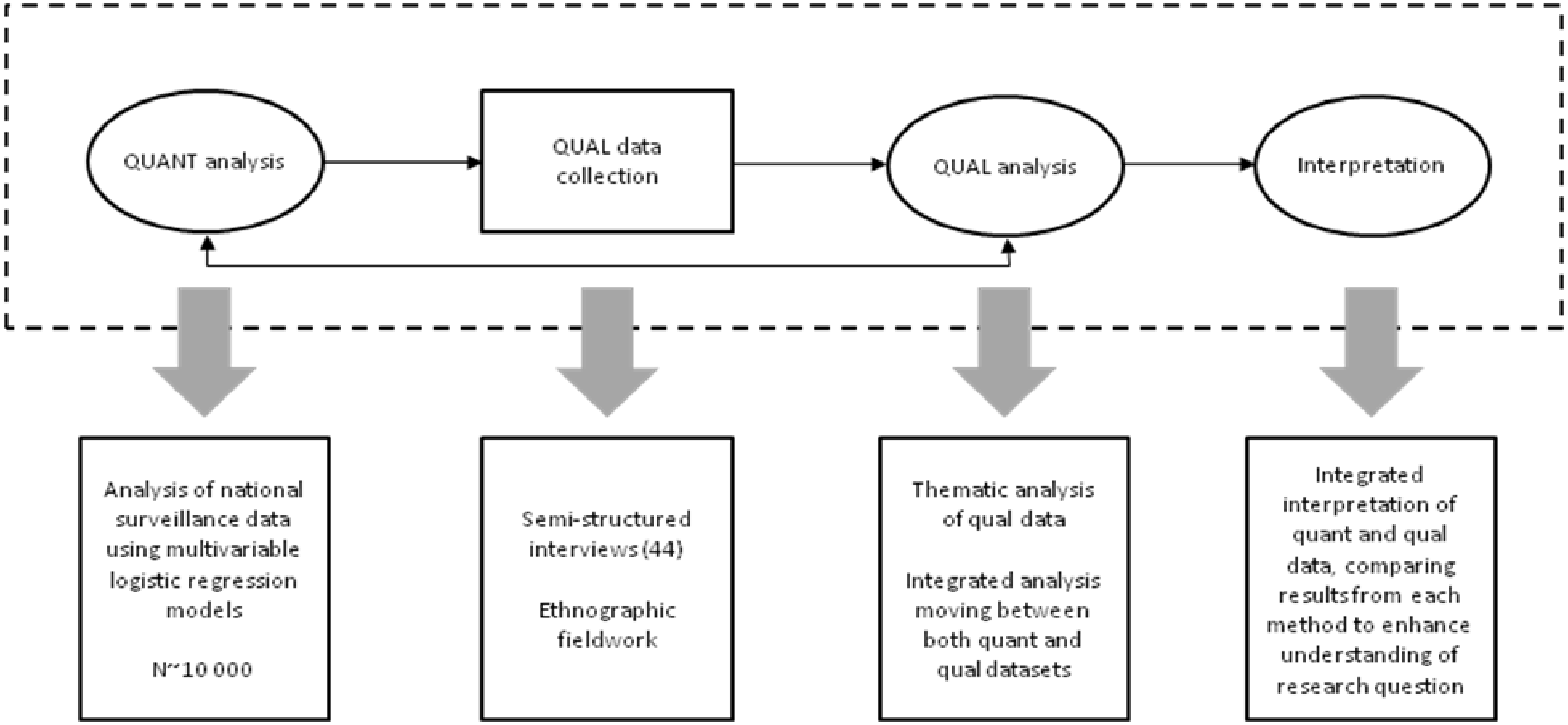
[64] Sequential explanatory mixed methods study designs have been well described in the literature. These designs comprise a quantitative phase where data are collected and analysed, followed by a qualitative phase where data are collected and analysed in order to explain and elaborate upon findings from the quantitative phase.

Figure 3.1: Mixed methods design for this study



QUANT, quantitative; QUAL, qualitative

Table 3.1: Gantt chart of quantitative and qualitative components of study (October 2009 – September 2012)

		October 2009 – September 2010				October 2010 – September 2011				October 2011 – September 2012			
		Q 1	Q2	Q3	Q4	Q 1	Q2	Q3	Q4	Q 1	Q2	Q3	Q4
Quant	NSHPC	▨	▨	▨	▨						▨	▨	
	SOPHID								▨		▨		
Qual	SSIs					▨	▨	▨	▨				
	B&S			▨	▨	▨	▨	▨	▨	▨			
	TCPM								▨				

Q, quarter; Quant, quantitative; Qual, qualitative; NSHPC, National Study of HIV in Pregnancy and Childhood; SOPHID, Survey of Prevalent HIV Infections Diagnosed; SSIs, semi-structured interviews; B&S, Body & Soul fieldwork; TCPM, Triumph of Christ Pentecostal Ministry fieldwork

Each dataset was kept analytically distinct and analysed using appropriate techniques. I moved between the datasets at the analysis stage to use findings from each analysis to identify key areas to be explored in the other datasets (Moran-Ellis et al. 2006). Linking also occurred at the interpretation stage, when results from the quantitative and qualitative analyses were compared, contrasted and combined (Sandelowski 2000). This has resulted in a thesis in which quantitative empirical chapters are interwoven with qualitative ones, three of which present fully integrated analyses (Chapters Five, Seven and Eight), concluding with chapters that synthesise findings from both approaches to answer the overarching research question (Chapters Ten and Eleven).

Although mixed methods are increasingly recognised within health research, methods such as secondary analysis of surveillance datasets and ethnography are rarely used in the context of mixed methods research with quantitative surveys, intervention studies and semi-structured interviews predominating (O'Cathain et al. 2007). It has been argued that anthropological approaches can provide “interpretive enrichment” (Béhague et al. 2008), providing a depth of understanding of the mechanisms by which epidemiological associations emerge. This is especially important as “epidemiology moves away from studying only biological phenomena towards exploring societal patterns and context, where causal pathways are likely to be longer, complex, diverse, and even cyclical” (Ibid.: 1705). By combining quantitative and qualitative approaches in this study my aim was to not only identify disparities in clinical outcomes and access to care, but to also understand how these disparities are produced, whilst exploring aspects of pregnancy in the context of HIV that women themselves found important. This would not have been possible using one methodological approach alone.

3.2 Quantitative methods - overview of datasets

The quantitative phase of this study comprises secondary analysis of epidemiological data from the National Study of HIV in Pregnancy and Childhood (NSHPC), the UK and Ireland’s active surveillance programme for HIV in pregnancy. The analysis of loss to follow-up after pregnancy uses a matched dataset comprising NSHPC data and data from the Survey of Prevalent Infections Diagnosed (SOPHID), a cross sectional survey coordinated by Public Health England (PHE) of all individuals diagnosed with HIV attending for HIV care in the UK. In this section I will describe these datasets in greater detail.

3.2.1 National Study of HIV in Pregnancy and Childhood (NSPHC)

The NSHPC, coordinated at University College London (UCL) Institute of Child Health (ICH), is a comprehensive population-based active surveillance programme that aims to include all women with diagnosed HIV who are pregnant or give birth in the UK and Ireland[65]. It was established in 1986 and currently has information on approximately 15,500 pregnancies reported between 1990 and 2011. It operates two voluntary quarterly parallel reporting schemes (figure 3.2) consisting of: (i) quarterly notification of all pregnancies and pregnancy outcomes among women with HIV on standardised forms[66] by approximately 240 National Health Service (NHS) maternity units in the UK and Ireland, and (ii) notification of children born to HIV infected mothers via the monthly reporting of rare conditions of childhood to the British Paediatric Surveillance Unit (Nicoll et al. 2000)[67]. Laboratory sources also contribute and some reports are directly obtained from specialist paediatric units looking after large numbers of children living with HIV. No names are requested or recorded and data collected include maternal date of birth, maternal country of birth, maternal ethnicity, date of arrival in UK, maternal source of infection, estimated date of delivery (EDD) or date of birth of infant, pregnancy outcome, delivery complications, maternal and infant HIV treatment, maternal clinical HIV stage, infant congenital abnormalities, and maternal CD4 counts and viral loads. Duplicate reports are deleted and records are linked by demographic data for previous pregnancies in the same mother. Major data queries detected at data entry are checked with NHS respondents. During the period of my PhD work, data

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[65] See http://www.ucl.ac.uk/nshpc/ for further details of NSHPC.

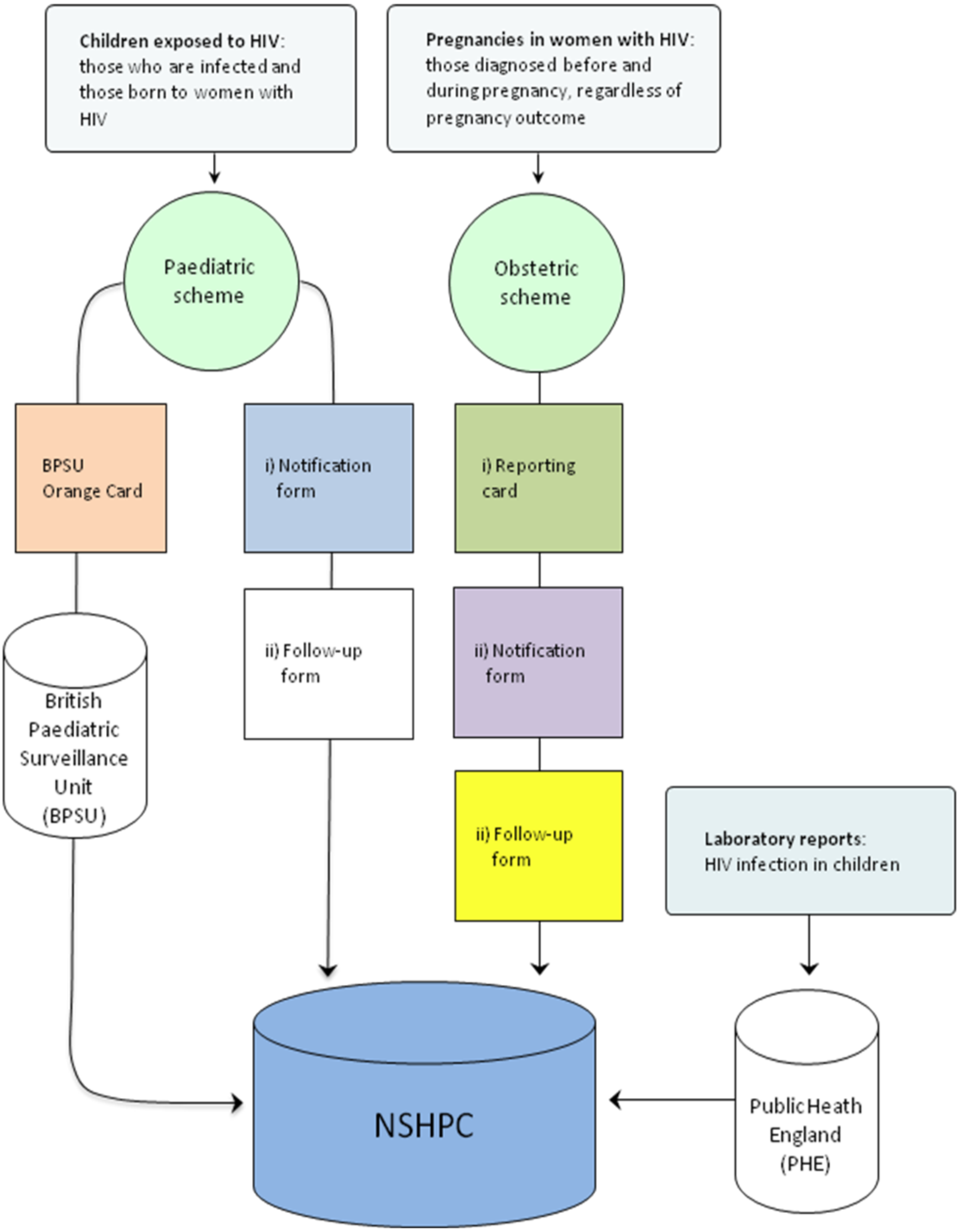
[66] NSHPC reporting forms are included in Appendix iv.

[67] The British Paediatric Surveillance Unit was jointly set up by the Royal College of Paediatrics and Child Health, the Institute of Child Health and the Public Health England (formerly the Health Protection Agency) to conduct active surveillance of rare conditions in childhood (including HIV).

were managed in Access 2003 and there were a series of checking mechanisms within Access and on export into Stata 11.2 (Stata Corporation, College Station, Texas, USA) to maintain data quality.

The NSHPC has national coverage and all women with diagnosed HIV-infection are eligible for inclusion. It is an active reporting system with a response rate of over 90% by NHS maternity units and it operates parallel obstetric and paediatric reporting schemes, ensuring that case ascertainment remains high. Uptake of HIV-testing in pregnancy has been over 80% since 2000 (Townsend et al. 2006) and was 97% in 2011 (Health Protection Agency 2012). A comparison with other sources of population surveillance data for HIV suggests that over 90% of HIV infections in pregnancies resulting in a live birth are diagnosed before or during pregnancy (Health Protection Agency 2009). Therefore, almost all pregnant women living with HIV in the UK will be diagnosed by the end of their pregnancy and should be reported to the NSHPC.

Figure 3.2: Reporting structure of the National Study of HIV in Pregnancy and Childhood (NSHPC)



Source: Adapted from Townsend (2009)

3.2.2 Survey of Prevalent HIV Infections Diagnosed (SOPHID)

The Survey of Prevalent HIV Infections Diagnosed (SOPHID) is a cross-sectional survey of all individuals aged fifteen and over with diagnosed HIV infection who attend for NHS HIV care in England, Wales and Northern Ireland within a calendar year (Smith et al. 2010). It was introduced in 1995 and is coordinated by Public Health England (PHE, formerly the Health Protection Agency). Scottish data are collected separately in Scotland by Health Protection Scotland and incorporated into UK data.

The survey is conducted twice a year in London[68] and annually outside London. Providers of HIV care are asked to compile a list of all individuals who have attended for HIV-related care. Data collected include: date of birth, sex, site of care, route of infection, ethnicity, date last seen (or date of death), and clinical markers. These anonymised data are transferred securely to PHE with duplicates identified and removed, and records pertaining to the same individual linked over time. SOPHID aims to provide estimates of prevalence of diagnosed HIV infection in the UK, as well as an epidemiological profile. As it is based on reports of people attending for HIV-related care, it is also used to plan and commission services, allocate funding and target national intervention programmes. Under-reporting to SOPHID is unlikely to be common as PHE actively follows up NHS sites that are under-reporting (Rice et al. 2011). Furthermore, there is a strong financial incentive for units to report to SOPHID as funding allocation for local HIV services are based on SOPHID estimates (Ibid.).

3.2.3 Record linkage between NSHPC and SOPHID

One of the objectives in this thesis is to explore the associations between loss to follow-up from HIV care after pregnancy and maternal ethnicity, African region of birth and duration of residence in the UK. The NSHPC does not collect data on women after pregnancy and SOPHID does not record pregnancy. It was therefore necessary to create, for the first time, a combined dataset using NSHPC and SOPHID data[69]. This allowed me to explore whether a woman reported to the NSHPC as pregnant in a given year attended for HIV care anywhere in England, Wales and Northern Ireland in the year following pregnancy[70].

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[68] For the purposes of SOPHID the survey of London includes Brighton, Hastings and Eastbourne.

[69] I am indebted to Cuong Chau, database manager for SOPHID and other colleagues at PHE for developing a matching strategy, and for implementing the matching algorithm and providing me with a list of matched records. I also acknowledge the role of my colleague Clare French at the NHSPC who collaborated closely with me on the creation of a joint dataset.

[70] This analysis is presented in Chapter Seven.

Women known by the NSHPC to be pregnant between 1999 and 2009 were matched to the SOPHID dataset by year of pregnancy[71]. A hierarchical matching strategy was implemented using limited identifiers collected in both the NSHPC and SOPHID such as sex, date of birth, residential information, country of birth and date of HIV diagnosis. Potential matches were identified by matching on female gender and date of birth in both NSHPC and SOPHID. Matches were then confirmed by matching across datasets using postcodes (or part postcodes) and other variables such as country of birth and date of diagnosis (table 3.2).

Country of birth is not collected by SOPHID and was obtained through linking of records between SOPHID and the HIV and AIDS New Diagnoses and Deaths database (HANDD) [72]. Deaths in women reported to have been pregnant to the NSHPC were also identified through linking of records to HANDD. Potential duplicate reports were identified and excluded from analysis. Pregnancies in women reported from Scotland to the NSHPC or reports to SOPHID from Scotland were also excluded as prior to 2008 Scottish reports to SOPHID were not linked over time, and it is therefore difficult to establish links between records in the same patient prior to 2008.

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[71] Women attending for HIV care during pregnancy should be reported to both the NSHPC *and* SOPHID in the same calendar year. Therefore residential details should be similar.

[72] The HIV and AIDS New Diagnoses and Deaths database at PHE collects information on new HIV diagnoses, first AIDS diagnoses and deaths in HIV infected individuals through voluntary reports by laboratories and clinicians in England, Wales and Northern Ireland. Records were linked to SOPHID through demographic data and soundex codes (an indexing system for encoding surnames). See http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/Page/1201094588891 (accessed 13 July 2013).

Table 3.2: Matching algorithm to create joint dataset from the National Study of HIV and Pregnancy and Childhood (NSHPC) and Survey of Prevalent HIV Infections Diagnosed (SOPHID)

Match level	Sex	Date of birth	Residential postcode to be matched with SOPHID	Other variables to be matched with SOPHID
1	✓	✓	Full/part PC (PS+) at Notification	
2	✓	✓	Full/part PC (PS+) at Delivery	
3	✓	✓	Part PC (PS) at Notification	
4	✓	✓	Part PC (PS) at Delivery	
5	✓	✓	Part PC (PD) at Notification	Country of birth
6	✓	✓	Part PC (PD) at Delivery	Country of birth
7	✓	✓	Part PC (PD) at Notification	Site of treatment
8	✓	✓	Part PC (PD) at Delivery	Site of delivery
9	✓	✓	Part PC (PD) at Notification	Date of HIV diagnosis +/- 30 days
10	✓	✓	Part PC (PD) at Delivery	Date of HIV diagnosis +/- 30 days

PS+ (postcode sector plus) = full postcode minus the last character e.g. NW9 5E
PS (postcode sector) = full postcode minus the last 2 characters e.g. NW9 5
PD (postcode district) = 1st half of postcode e.g. NW9

3.2.4 Limitations of matching NSHPC and SOPHID datasets

There are limitations in matching records across two large national epidemiological datasets. As SOPHID and NSHPC do not share a unique identifier, the matching algorithm described in the previous section (which employed a series of increasingly fuzzy identifiers) was used. This matching strategy was successful in that nearly 90% of NSHPC records were matched to a corresponding record in SOPHID. *Not* being matched across the datasets was associated with reporting area (probably a function of SOPHID being conducted twice yearly in London and annually elsewhere, giving London centres greater opportunity to collect data) and earlier time period. Women from Southern Africa and those who arrived in the UK after conception were also more likely not to be matched which may be because this was a more mobile population[73] or

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[73] Women may have moved between pregnancy (the postcode reported to NSHPC) and attendance for HIV care (the postcode reported to SOPHID).

because these women were more likely not to have ever attended for care. There was no evidence of an association between ethnicity and a NSHPC record being matched with one in SOPHID.

A recent audit on loss to follow up in the general adult HIV-positive population in the UK found that one in five people not linked to SOPHID had in fact attended for care in the UK (Clay 2013). The authors conclude that the reasons why some patients attending for HIV care in the UK are not captured in SOPHID are unclear (Ibid.). As discussed earlier, under-reporting to SOPHID is unlikely to be a major factor due to the financial implications. Coding errors in variables in the NSHPC or SOPHID, such as gender, date of birth or residential information, would result in a non-match and an over-estimate of the proportion of women who were lost to follow-up. Furthermore, changes in date of birth or residential postcode (which occurs in the context of undocumented migration and highly mobile populations) would also prevent matching. Some women who were not matched may have disengaged from care after pregnancy and therefore would not be reported to SOPHID, leading to underestimation of loss to follow-up. To address this I coded all pregnancies that were not matched as lost to follow-up and repeated all multivariable analyses to explore the effects on estimates (Chapter Eight) .

3.3 Quantitative methods - analysis of NSHPC datasets

My quantitative analyses, presented in Chapters Four, Five, Seven and Eight, are based on the Q87 NSHPC dataset, which comprises data collected by the NSHPC up until the end of June 2011[74]. I created my own dataset from this by checking existing variables and removing variables that were not required for my analyses. I regrouped some of the existing variables according to my own requirements and removed records according to the exclusion criteria described in section 3.3.1. For the specific purposes of this study I created exposure variables from existing data that have not been used in previous NSHPC analyses. These were maternal ethnicity (comprising white British and African categories as opposed to ethnic categories based on the England and Wales Census), maternal African region of birth, and maternal duration of residence in the UK. Furthermore I created two new outcome variables (maternal viral load at delivery and timing of antenatal booking) that have not previously been explored within the NSHPC. This involved merging raw data from the NSHPC Access database into the Q87 dataset.

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[74] The most up to date dataset available at the completion of the quantitative phase of my PhD research.

Finally, I created a range of variables to explore loss to follow-up after pregnancy for the first time in UK national surveillance datasets. I was closely involved in the matching process between NSHPC and SOPHID and was responsible (with my NSHPC colleague Clare French) for merging the matched SOPHID dataset with the Q87 NSHPC dataset.

3.3.1 Exclusion criteria

All pregnancies reported to the NSHPC in the UK were eligible for inclusion in the study if the year of delivery or estimated date of delivery (EDD) was between 1990 and 2010. Pregnancies before 1990 were excluded as there were little data recorded on them. Pregnancies with a delivery date or EDD in 2011 were excluded as these pregnancies were mainly ongoing by the completion of analyses and data on these pregnancies were therefore incomplete. Data from Ireland were excluded, as the focus of this thesis is pregnancies in African migrant women living with HIV in the UK. Health and social care policy, which is likely to impact women’s access and experience of healthcare, differs between the UK and Ireland. Furthermore the qualitative phase of this study was conducted within the UK and findings cannot be extrapolated to inform understanding of clinical outcomes and access to care in Ireland.

The dataset was further restricted by the following criteria (also see figure 3.3):

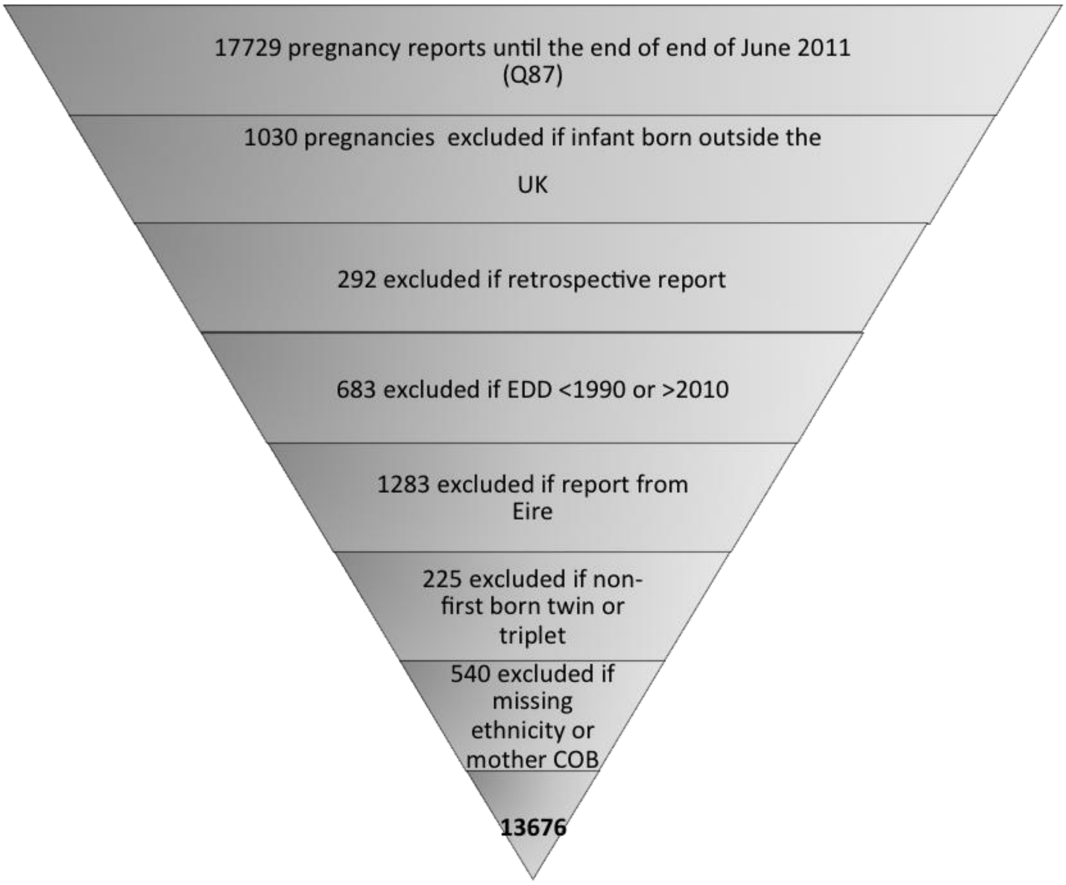
1. If the report was “retrospective”. Retrospective reports are in pregnancies originating early in the NSHPC study period that were reported a considerable time after a woman had delivered, regardless of whether a woman was diagnosed before or after delivery. These reports (292) often lacked detailed data on maternal demographics and the majority pertained to pregnancies with an EDD before 1990.

2. If the report pertained to a twin or triplet who was not the first-born. This avoids duplicate inclusion of the same mother in the same pregnancy in analyses.

3. If the reported pregnancy resulted in a child born outside the UK or Ireland. These reports have very little maternal data reported and may reflect care received outside the UK.

4. If maternal ethnicity and country of birth were missing as they are main exposure variables of interest for the quantitative analyses in this thesis.

Figure 3.3: Restriction of the main study dataset (NSHPC)



EDD, estimated date of delivery; COB, country of birth

The dataset was further restricted for the analyses of the five key outcomes: late antenatal booking, not receiving ART during pregnancy, detectable maternal HIV viral load at delivery, vertical transmission of HIV and loss to follow-up from HIV care in the year after pregnancy. Pregnancies were included if year of delivery or EDD was after 2000. This corresponds with wider use of HAART in pregnancy and more consistency in clinical practice and laboratory monitoring than in the previous decade. Furthermore, the majority of pregnancies reported to the NSHPC were during this time period (12,193/13,676; 89%). Pregnancies were also excluded in analyses of key outcomes if the mother was diagnosed with HIV *after* delivery as the clinical and service-related outcomes explored in this thesis relate to HIV care and interventions received *during* pregnancy. The 286 women diagnosed after delivery[75] would not have had the opportunity to access this. Further exclusion criteria specific to each analysis

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[75] These are different from the aforementioned “retrospective” reports as they *all* pertain to pregnancies where maternal HIV diagnosis was after delivery.

are presented in table 3.3 and discussed in detail in the relevant chapters.

3.3.2 Definition of key exposure variables

This thesis sets out to explore the association between key clinical and service-related outcomes, and maternal ethnicity, African region of birth and maternal duration of residence in the UK. I now describe these key exposure variables in detail. For each of the following variables, I completed missing values from data reported in other pregnancies reported to the NSHPC in the same woman when possible.

Maternal ethnicity

Maternal ethnicity in the Q87 dataset was based on recorded ethnicity on notification forms. This was most likely to be based on self-reported ethnicity on hospital records. Where missing, maternal ethnicity was recorded as the same as infant ethnicity (if reported, and if the infant was not of mixed ethnicity). Ethnicity categories reported to the NSHPC correspond to England and Wales Census ethnic classification. As discussed in Chapter One, UK census categories were not developed or validated for public health research. Furthermore these broad ethnicity categories may not capture differences between those who migrate to the UK, and those born in the UK who have descended from African backgrounds. The focus of this thesis is migrant women and therefore maternal ethnicity in the analyses presented in this thesis is based on reported ethnicity (categorised according to England and Wales Census classification) and maternal country of birth. I categorised as women as “African” if they were of Black African ethnicity *and* were born in Sub-Saharan Africa[76]. “White British” pertains to women of White ethnicity who were born in the UK. All analyses except for the description of demographic trends (Chapter Four) comprise only pregnancies in white British and African women due to small numbers in the other ethnic groups.

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[76] Women of mixed, white or other ethnicities who were born in Sub-Saharan Africa were not included in this group as they are likely to have different migratory experiences due to cultural, political and socioeconomic differences.

Table 3.3: Analysis specific exclusion criteria

Analysis (Chapter)	Time period (EDD/year of delivery)	Exclusions	Outcome	Outcome missing n (%)	Number in analysis
Time trends in ethnicity, African region of origin and duration of residence in the UK (4)	1990-2010	Non first-born twins/triplets.	N/A	N/A	(numbers vary)
Uptake of ART in pregnancy (5)	2000-2010	Non- first born twins/triplets. TOPs, miscarriages, ectopic pregnancies.	No ART in pregnancy	217 (2.6)	9214
Viral load at delivery (5)	2000-2010	All outcomes except live births. Twin pregnancies. No HAART in pregnancy.	Detectable HIV viral load at delivery	1285 (17.6)	7290
Infant HIV status (5)	2000-2010	All outcomes except live births. Twin pregnancies.	Vertical transmission	1177 (13.9)	7277
Timing of antenatal booking (7)	2008-2010	Non first-born twins/triplets. TOPs and ectopic pregnancies. Pregnancies in women who arrived in UK after conception.	Late antenatal booking	874 (26.1)	2481
Follow-up after pregnancy (8)	2000-2009	Non first-born twins/triplets. Pregnancies notified in Scotland. Pregnancies in women who moved abroad during pregnancy.	Failure to return for HIV care in the calendar year after pregnancy	749 (10.4)	7235

EDD, estimated date of delivery; N/A, not applicable; TOP, termination of pregnancy; ART, antiretroviral therapy; HAART, highly active antiretroviral therapy.

Maternal African region of birth

I based maternal African region of birth on reported country of birth and grouped according to United Nations classification of Sub-Saharan African regions: Eastern, Western, Southern and Middle Africa (table 3.4). I accept that boundaries of countries and regions in Sub-Saharan Africa are somewhat arbitrary with origins in colonial history and that they may not correspond to cultural groups. However in the absence of more useful information such as languages spoken, I use these groupings as a heuristic device to explore heterogeneity within African women in terms of reasons for migration, economic circumstances and culture.

Table 3.4: United Nations geographical sub-regions (Sub-Saharan Africa)

United Nation Region	Countries
Eastern Africa	Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Malawi, Mauritius, Mayotte, Mozambique, Réunion, Rwanda, Seychelles, Somalia, Uganda, United Republic of Tanzania, Zambia, Zimbabwe
Southern Africa	Botswana, Lesotho, Namibia, South Africa, Swaziland
Western Africa	Benin, Burkina Faso, Cape Verde, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Saint Helena, Senegal, Sierra Leone, Togo
Middle Africa	Angola, Cameroon, Central African Republic, Chad, Congo, Democratic Republic of the Congo, Equatorial Guinea, Gabon, Sao Tome and Principe

Source: http://unstats.un.org/unsd/methods/m49/m49regin.htm (accessed 06 May 2011).

Maternal duration of residence in the UK

I defined duration of residence in the UK for African women as the length of time in years between reported date of entry to the UK and estimated date of conception. I estimated conception date to be the date of the last menstrual period, which I defined as day 280 *before* EDD. If EDD was unavailable, then it was estimated by subtracting gestation in days from infant date of birth. There is no clear consensus within epidemiological literature as to how to categorise duration of residence with authors deploying different measures and groupings (Jayaweera et al. 2010, Teitler et al. 2012, Urquia et al. 2012). Due to a large proportion of missing data on duration of residence in the UK (36.7%) I categorised women in broad groups, which were based on the median duration of residence in the UK (four years). I hypothesised that women who had migrated to the UK *after* conception may be a particularly vulnerable group in terms of access to healthcare and grouped these women separately. Duration of residence was therefore grouped as follows: "≥4 years", "< 4 years (before conception)" and "since conception".

3.3.3 Data management

The five outcome variables are described in detail in the relevant chapters. I defined and categorised other key potential confounding variables as follows.

Maternal age corresponded to maternal age at delivery in years and I categorised it as "<25", "25-34" and "≥35". These groupings correspond with known obstetric risk in younger and older women. Maternal injecting drug use was a binary variable ("yes" or "no") and was defined as whether the mother's likely infection route was injecting drug use or not. I defined year as year of birth or EDD and treated it as a categorical variable.

I grouped first recorded HIV viral load in pregnancy in RNA copies/ml into three categories according to accepted clinical cut-off points ("undetectable", "50-10,000", "≥10,000"), which corresponds to undetectable, moderate, and high HIV viral loads. "Undetectable" viral load was defined as viral load <50 copies/ml. I grouped first recorded HIV CD4 count in pregnancy in cells/mm^3 into three categories ("≥350", "200-349", "<200"), which reflects mild, moderate and advanced immunosuppression and corresponds to the threshold for initiation of antiretroviral therapy (ART)[77]. Gestational age was based on completed weeks of gestation and grouped into two categories ("≥37 weeks", "<37 weeks"), which corresponds to term and preterm delivery. This also allowed for censoring at thirty-eight weeks due to routine elective caesarean section at thirty-eight weeks for the prevention of vertical transmission.

I defined type of highly active antiretroviral therapy (HAART)[78] as "NRTI only" (nucleoside reverse transcriptase inhibitor only), "NNRTI-based" (non-nucleoside reverse transcriptase inhibitor based), "PI-based" (protease inhibitor-based) and

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[77] Current UK guidelines advise the initiation of ART at a CD4 count of <350 cells/mm^3 (Williams, et al. 2012) CD4 count<200 is evidence of advanced immunosuppression and is associated with an increased incidence of opportunistic infection.

[78] HAART being classified as a treatment combination of three of more antiretrovirals agents.

"NNRTI and PI-based" (exposure to both PI and NNRTI)[79]. Duration of ART at delivery was measured in weeks and I categorised it as "on HAART at conception", "12-40 weeks", "2-11 weeks", "<2 weeks" and "none".

I examined all data for improbable values and these values were checked against written records and amended accordingly or coded as missing. I also checked the dataset for duplicate entries, which I subsequently removed.

3.3.4 Missing data

Data were checked for missing values on exposure variables, the five key outcomes (not receiving ART in pregnancy, detectable viral load at delivery, vertical transmission of HIV, late antenatal booking and loss to follow-up) and potential confounding variables. Records with missing exposure and outcome data were excluded from analysis for the exposure and outcome of interest[80]. Records with missing data on confounding variables were also dropped from the final multivariable models. Clinical and demographic characteristics of pregnancies with missing data were compared with pregnancies with data recorded using the χ^2 test to investigate potential bias.

The NSHPC is an active surveillance programme which depends on respondents' reporting of information about pregnancies. Data were inevitably missing for many variables, however on the whole this was minimal. In terms of the key exposure variables, data on ethnicity and maternal country of birth were missing in only 0.8% and 1.5% of 11,090 eligible pregnancies[81] respectively. Given these small proportions, missing data are unlikely to bias estimates significantly.

Data on maternal duration of residence in the UK were much less complete. After excluding 1464 pregnancies in women who had been born in the UK, 36.7% of pregnancies did not have maternal duration of residence in the UK reported. Missingness was associated with diagnosis during pregnancy, outcome other than live birth and earlier gestational age at delivery (all $p<0.001$) suggesting that this may be due to lack of opportunity to record this information. The mechanism for missing data on maternal duration of residence in the UK is likely to be *missing not at random* (MNAR)

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[79] This excludes newer classes of antiretroviral agents such as integrase inhibitors and CCR5-receptor antagonists. However, these agents were very rarely used at the time of analysis in 2011.

[80] Except for the analysis of maternal HIV viral load at delivery where an imputed variable was used (Chapter Seven).

[81] Pregnancies reported between 2000 and 2010 in women who were of Black African, white or unknown ethnicity and who were diagnosed with HIV prior to the end of pregnancy.

(Donders et al. 2006). That is, the probability of maternal duration of residence being missing is likely to be dependent on both the actual missing value (how long a woman has been resident in the UK)[82] *and* other reported factors such as whether HIV was diagnosed before or during pregnancy, gestation at delivery and pregnancy outcome. (figure 3.5).

As a first step, missing date of entry into the UK was completed from previous pregnancies reported to the NSHPC where available. Date of entry into the UK is not available in other large HIV datasets such as SOPHID, HANDD and UK Collaborative HIV Cohort (UK CHIC)[83]. I therefore considered a number of further approaches to handle missing data in this variable. I discounted Multiple Imputation by Chained Equations (MICE)[84] (Rubin 1987) as the fraction of missing information (FMI)[85] was >35%. Furthermore the number of imputed datasets should exceed FMI which for the purposes of my analyses would be >37 imputed datasets which is computationally difficult. The structure of my dataset was complex with a mix of categorical and continuous data (mainly non-normally distributed), which would be difficult to model, and a set of variables (such as maternal ethnicity and date of entry into the UK) that need to remain constant in the case of sequential pregnancies in the same woman during an imputation process. Most importantly, however, is the likelihood that the mechanism of missingness was MNAR, in which case MICE would not be reliable. Following discussion with the MRC Biostatistics Unit in Cambridge[86] it became apparent that MICE was not an appropriate approach in handling missing duration of residence in the NSHPC dataset. Other statistical approaches such as inverse probability weighting were beyond the scope of my PhD and would also be unreliable if data were MNAR. I was therefore limited in my ability to address the large proportion of missing data on maternal duration of residence in the UK and restricted my analyses to pregnancies

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[82] This is hard to predict as duration of residence may not be reported in women who have been in the UK for a longer period of time as it is not considered relevant, or it may not be overlooked in women who have recently arrived in the UK (who are likely to also be newly diagnosed with HIV) due to more pressing factors to address during pregnancy.

[83] This is a cohort study comprising over 47,200 patients from some of the largest HIV clinical centres in the UK which pools routinely collected clinical and demographic data. See UK Chic website for further information at http://www.ukchic.org.uk/.

[84] MICE is an approach used to handle missing data involving the creation of several datasets where missing values are imputed based on a model specified by the analyst. Analysis is then conducted on each of the imputed datasets and the parameter estimates combined. This method is increasingly used and recognised as a more robust method of handling missing data although it has important limitations.

[85] FMI approximates to the proportion of missing information in a variable. MICE models are not reliable with FMI>20%.

[86] The MRC Biostatistics Unit at Cambridge has particular expertise in MICE with members of their team having written the MICE commands for Stata and providing regular teaching on missing data and imputation techniques.

where this was reported. This is likely to introduce bias but it is difficult to predict in what way[87].

With regards to key outcomes, data on whether a woman received ART in pregnancy was recorded well with data available in nearly 98% of pregnancies. Approximately 14% of records had missing data on infant HIV status. Again, this was strongly associated with later year of report (2007-2010) and largely reflects delays in reporting final laboratory results of infants' HIV-antibody tests. Previous sensitivity analyses have shown that missing infant HIV-status is likely to have a minimal effect on vertical transmission estimates for UK data (Townsend et al. 2008a). Analyses exploring antenatal booking were restricted to pregnancies after 2008 by necessity as this was when booking date started to be routinely collected by the NSHPC, with smaller numbers included in this analysis than others presented in this thesis. Data on antenatal booking were not available in over a quarter of eligible pregnancies. Missing data were associated with reporting region and may reflect variations in reporting practice. They were also associated with miscarriage, severe prematurity and continuing pregnancies suggesting a lack of opportunity to record booking date. There was no association between missing booking date and ethnicity, African region of origin or duration of residence in the UK. Although I cannot exclude the possibility of bias being introduced by missing data in this analysis it appears unlikely.

The proportion of missing data on maternal viral load at delivery was much higher than other outcome variables at 43.7%[88]. An imputed viral load variable was used if the last viral load in pregnancy was undetectable in an effort to reduce this and a further 1904 values were added using this approach[89]. This reduced the proportion of missing viral load at delivery data to 17.6%. All analyses were performed using the non-imputed and imputed variable with little difference in results apart from reducing confidence intervals, which increases confidence in the validity of the model using imputed values. An important predictor of missing delivery viral load was earlier year of report, which is

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[87] For example, women with shorter duration of residence in the UK may have been less likely to have date of entry into the UK reported, and would be excluded from analyses. These women may also have poorer outcomes, which would not be reflected in my analyses.

[88] This is likely to be largely due to maternal viral load samples not being sent in the twenty-eight days prior to delivery or seven days subsequent (the time frame I use in my analyses for viral load at delivery).

[89] The proportion of missing viral load data was higher in pregnancies where the first viral load in pregnancy was undetectable compared with those where it was detectable (57.1% vs. 47.1%, $p<0.001$). See Chapter Five for a detailed description of the use of this imputed variable in this analysis.

likely to reflect changes in clinical practice in virological monitoring over time[90]. Missing delivery viral load data was also associated with arriving in the UK after conception, possibly indicating decreased access to services. It may also be that these women were more likely to have a detectable viral load, which would have led to an underestimation of the association between viral load at delivery and duration of residence in the UK.

3.3.5 Statistical methods

Data were analysed using Stata 11.2 (Stata Corporation, College Station, Texas, USA). For analyses of trends I used the *Bonferroni correction* (Bland et al. 1995) which accounts for multiple comparisons within a group by adjusting the statistical significance level used for each test, minimising the chance of spurious positive results. For a given outcome, a Chi-square test was performed to compare pregnancies across different ethnicity, African region and duration of residence groups. These groups were then compared for each outcome using univariable and multivariable logistic regression models to estimate odds ratios and adjusted odds ratios, with 95% confidence intervals. A priori confounders were included in final multivariable models[91]. Other variables were included if their inclusion improved model fit. This was assessed using likelihood ratio tests, with a significance level of $p<0.05$. Approximately 26% (3535/13,676) of pregnancies reported to the NSHPC between 2000 and 2010 were in women who had had a previous reported pregnancy. It may not be appropriate to treat sequential pregnancies in the same woman as independent pregnancies as there are likely to be maternal-level factors not captured by the NSHPC, such as adherence to ART, that exert an effect on pregnancies in the same woman. To account for potential clustering at a maternal level in sequential pregnancies where appropriate for some outcomes I used robust standard errors (Kirkwood et al. 2003)[92].

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[90] Between 2000 and 2010, the importance of viral load monitoring was increasingly recognised with the first specific guidance recommending maternal HIV viral at 36 weeks' gestation and at delivery in 2005 (Hawkins, et al. 2005).

[91] Year of delivery or EDD was included as an *a priori* confounder in all analysis to allow for changes in clinical practice and measurement tools over time. Other *a priori* confounders are described in the relevant chapters.

[92] Standard statistical approaches, which are based on an assumption that observations in a dataset are independent of each other, may not be appropriate for clustered data, that is if observations in a cluster are more similar to each other than observations in the rest of the dataset. Examples of this include repeated measures (or pregnancies in the case of my own research) in the same patient, multiple measures (such as observations on both eyes in one patient), and study designs where individuals are grouped (such as cluster randomised trials). In these cases a variety of approaches can be used to allow for clustering. Having considered approaches such as *random effects models,* I decided that robust standard errors were the most appropriate technique to handle clustering in my dataset. Robust standard errors are based on

3.3.6 Ethical considerations

The NSHPC has London Multi-Centre Research Ethics Committee approval (MREC/04/2/009). SOPHID does not require ethical approval as it fulfils a surveillance purpose (Tariq et al. 2012b). Public Health England (formerly the Health Protection Agency until April 2013) is registered under the Data Protection Act 1998 (registration number Z7749250) to handle data for diagnostic, public health and other purposes. It is also registered under Section 251 of the Health and Social Care Act 2001 and has approval from the Patient Information Advisory Group (PIAG) and the National Information Governance Board for Health and Social Care (NIGB) to handle data for purposes that include surveillance and the control of disease, even where specific patient consent has not been given[93] .

An important ethical consideration to be taken into account during the quantitative phase of this study was the grouping of pregnancies according to maternal country of birth. I do not present data by maternal country of birth in this thesis as in some cases there were small numbers of women from certain countries (less than five) which may lead to these women being identified by healthcare professionals[94]. Instead data on maternal country of birth are grouped and presented as African region of birth as described earlier.

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the variability in the data, rather than that assumed by statistical models, and adjust the standard error accordingly.

[93] See Public Health England's website for further details on surveillance and confidentiality (http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Surveillance/SurveillanceAndConfidentiality/, accessed 26 September 2013).

[94] This could have been addressed by restricting analyses to pregnancies in women born in Uganda, Nigeria, Zimbabwe, South Africa and Zambia (the largest groups) but this would exclude other groups of women and shift the focus of this thesis to women from these countries rather than African migrant women more broadly.

3.4 Qualitative methods

The second phase of the mixed-methods research presented in this thesis uses an ethnographic approach to understand the experiences during and after pregnancy of African migrant women living in London. Ethnographic methods are relatively under-utilised in health research (Savage 2000, Lambert et al. 2002, Mulhall 2003). Ethnography has its roots in social anthropology and the work of key figures such as Malinowski ([2010] 1954), Boas ([1986] 1928) and Mead ([2001] 1928). There is no clear consensus as to what defines ethnography (Hammersley et al. 2007), however ethnographic research is distinguished from other forms of qualitative approaches by its explicit focus on the understanding of cultural phenomena within groups of people using a range of methods. Traditionally the cornerstone of ethnographic research has been participant observation involving a researcher's prolonged immersion and participation in the daily lives of people in a group (Ibid.). The combination of observations, informal conversation, formal interviews, and analysis of documents and other cultural resources can facilitate a multidimensional understanding of cultural phenomena that may not be possible with methods such as formal interviews alone (Reeves et al. 2008).

My decision to use an ethnographic approach in my work was informed by my previous training as a medical anthropologist which gave me both a methodological and intellectual plane in which to orientate myself. By using an ethnographic approach I aimed to gain a depth of understanding of pregnancy in African migrant women living with HIV that does not currently exist within the literature. Previous qualitative studies in the UK on HIV and pregnancy, although yielding important insights[95], have been based solely on semi-structured or in-depth interviews with women and their health care providers. By using a variety of methods (including participant observation), grounding myself within anthropological literature and seeking a deep engagement with cultural data on traditional themes of interest in anthropology such as religion, pollution and taboo, and marginality, I have sought to reflect the world of my participants whilst critically engaging with key theoretical constructs that emerged (Golden-Biddle et al. 1993). My aim has been to provide a detailed account and ethnographically-informed[96] analysis of what it is to be an HIV-positive pregnant African woman living in London.

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[95] This literature is summarised and reviewed in the previous chapter.

[96] By this I mean focusing on cultural data such as religion, taboo and marginality and grounding my analysis in relevant ethnographic and theoretical work.

My ethnographic approach (which is described in detail in later sections) comprised mainly semi-structured interviews with pregnant African women living with HIV and those involved in their care, and participant observation in London in NHS clinics, a Pentecostal church and a charity that supports families affected by HIV. This work was supported and contextualised by attendance at professional meetings and conferences and analysis of documents and other media where relevant.

3.4.1 Locating my field

The focus of this thesis is pregnant African women living with HIV. This is not a natural cultural group with regular interaction, making an ethnographic field, in the traditional sense, difficult to locate. Historically ethnographic research has been based on work within a single site. However, it is increasingly recognised that this approach may not be suited to questions asked within a contemporary postmodern society. Marcus (1995) traces the emergence in the past three decades of *multi-sited ethnography* in response to the transformation of the global cultural economy. As discussed in Chapter One, the world we live in challenges previous notions of world systems, discontinuous spaces and the "isomorphism of space, place and culture" (Gupta et al. 1992: 7). This is an era of interconnected space with transnational circulations of economic, cultural and symbolic capital as well as unprecedented flows of people across borders[97]. "Cultures" and "peoples" can no longer be "plausibly identified as spots on the map" (Ibid: 10), and ethnography that fails to attend to this risks replicating static notions of culture. Multi-sited ethnography attempts to engage with this transformation of space by acknowledging that meaning is created in various interconnected sites of activity (Marcus 1995)[98].

African migrant women living with HIV in London are a heterogeneous group comprising women of different ethnicities, linguistic communities, religions, migration experiences and social circumstances. Some will have been diagnosed with HIV many years ago; whilst for others their HIV diagnosis will be much more recent. This is a group of women who are scattered across one of the largest cities in the world, sometimes without stable housing, with no obvious focal convergent point. To borrow from Paul Farmer, they are "splintered groups of people bound together by a shared lab

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[97] Eloquently captured in Appadurai's notion of *–scapes* as discussed in Chapter One (Appadurai 1996).

[98] This multiplicity of meaning extends beyond geographical space, into considerations of subjectivity and an understanding of the value of multiple vantage points in avoiding naïve and romanticised representations of subjects. Donna Haraway's essay on situated knowledge and the value of "partial perspective" is an important reference here (1988).

result" (Farmer 2004: 71). Furthermore, HIV is a highly stigmatising condition and one that women may go to great lengths to hide.

The *rhizomic*[99] nature of HIV-positive African women's lives in London demanded a multi-sited approach to fieldwork. Rather than locating women in a single naturally occurring site (which was not feasible) I decided to "follow the people" (Marcus 1995: 106) and go to places where women may go. This was primarily NHS HIV antenatal clinics, as they are one of the few spaces where women may feel that they can openly acknowledge their HIV-positive status. However, I also "followed" women into other sites that shaped their day-to-day experiences, such as a London-based HIV charity and a Pentecostal church on the outskirts of the city. In doing so, I hoped to not only encounter pregnant African women living with HIV but also those around them who are involved in producing what it means to be pregnant, HIV-positive and African in London. These other actors included healthcare professionals, charity professionals, church pastors, community members and other groups of people living with HIV.

The practice of multi-sited ethnography is not straightforward in that it involves the constant repositioning of oneself as an ethnographer with shifting allegiances, commitments, and roles (Marcus 1995). During the course of my own work I found myself rapidly cycling through the roles of anthropologist, doctor, colleague, volunteer and friend; many of these concurrently. However, I see this constant repositioning of myself in the field as akin to using a set of different camera lenses, allowing me to gain a multiperspectival view of my research question.

3.4.2 Introducing my field

London is the most populous city In Europe with a population of 8.2 million, of whom 3 million were born outside of the UK, a 54% increase since 2001[100]. It is the most ethnically diverse area in England and Wales with 40% of people living in London from a minority ethnic group (Ibid.). Just over 13% of people residing in London are of Black African[101] ethnicity, compared with 3% in England and Wales as a whole (Ibid.). African migration to the UK dates back to Roman times when African soldiers served in Roman legions and increased during the seventeenth and eighteenth centuries during the

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[99] See Chapter One for a discussion of Appadurai's use of the term *rhizome* to capture the deterritorialisation and interconnectedness of the contemporary globalised world.

[100] Data obtained from Table KS201EW of the 2011 Census for England and Wales available at http://www.ons.gov.uk/ons/datasets-and-tables/index.html (accessed 06 August 2013).

[101] This includes people born in the UK and abroad.

transatlantic slave trade. London, as one of Britain's main trading ports along with Liverpool and Bristol, was a focal point in African slave migration during this time (Grillo et al. 2008). The mid-twentieth century saw a dramatic increase in migration to the UK from Britain's former colonies and Commonwealth states, in response to favourable immigration policies designed to attract migrant workers to rebuild the post-war British economy. Although this levelled off with the introduction of immigration restrictions in the 1960s, migration to the UK from Sub-Saharan Africa for economic and political reasons has continued.

London also has the highest HIV prevalence in the UK, with thirty of the city's Local Authorities having a high prevalence of diagnosed HIV (>2 per 1000 persons), and eighteen of these having the highest prevalence rates in the country (Public Health England 2013). Over 31,000 people living in London with diagnosed HIV accessed care in 2011, representing just under 50% of all people accessing HIV care in the UK (Ibid.). Furthermore, the five NHS centres that report the greatest numbers of pregnancies in women diagnosed with HIV are all in London[102].

As the most ethnically diverse city in the UK with a sizable African population and large numbers of people accessing HIV care, and also my home for over thirteen years, London was an ideal site for my fieldwork.

As discussed earlier, my ethnographic research was not confined to a single site; rather it encompassed several sites across the city. Firstly I recruited pregnant African women living with HIV and healthcare professionals in three specialist NHS HIV antenatal clinics in London, choosing to recruit from more than one centre in order to maximise the chances of recruiting and to reflect the diversity of clinical practice and clinic populations in London. These three sites are among the five hospitals reporting the largest numbers of pregnancies in HIV infected women in the UK between 2000 and 2010[103], each centre looking after approximately forty to fifty pregnant HIV-positive women each year. They are in boroughs (Hackney, Newham and Lambeth) of great ethnic diversity[104], and also substantial deprivation with all three classified as among the

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[102] Data from the Q87 NSHPC dataset with reports up to and including June 2011.

[103] Data from the Q87 NSHPC dataset with reports up to and including June 2011.

[104] All three hospitals are in boroughs that are ethnically diverse, with the proportion of the population who are Black African approximately 11% to 12%. Data obtained from 2011 England and Wales Census table KS201EW available at http://www.ons.gov.uk/ons/datasets-and-tables (accessed 24 September 2013).

thirty most deprived local authorities in England[105] (figure 3.4). All the antenatal clinics were based within NHS hospitals, which are bound by Department of Health regulations to provide maternity services, including antenatal care, to all women free of charge regardless of residency status (Department of Health 2011)[106].

Homerton University Hospital is in Hackney in East London, a borough which is the second most deprived in the UK by multiple indices of deprivation (Leeser 2011). The hospital was opened in 1986 and sees over 322,000 patients a year. Its HIV department currently looks after over 850 patients (Jane Anderson, Homerton University Hospital NHS Foundation Trust, personal communication, 28 September 2012), of whom over half are women of reproductive age and three quarters are first-generation Africans[107]. Newham University Hospital opened in 1983 and is in the borough of Newham, also in East London. It was thrust into the spotlight in 2012 as the host borough for the 2012 Olympics and has been the site of rapid regeneration. However the borough remains extremely socioeconomically deprived and is ranked third in the UK in terms of deprivation (Leeser 2011). Over 900 patients access the hospital's HIV services a year, of whom nearly 60% are women and 70% are African (Rebecca O'Connell, Barts Health NHS Trust, personal communication, 22 August 2013). African HIV-positive patients attending for care in clinics in East London face significant economic and social hardship in comparison to other ethnic groups, with 50% having insecure immigration status and 40% not having enough money to cater for their basic needs (Ibrahim et al. 2008). My final NHS site was St Thomas' Hospital, one of the oldest hospitals in London with its modern incarnation opening in 1896. It is situated in Lambeth in South London, a borough ranked twenty-ninth on multiple indices of deprivation (Leeser 2011). It has one of the largest HIV clinic populations in the UK (approximately 3000 patients) of whom over a quarter are Black African and nearly a third are female (Annemiek de Ruiter, Guys and St Thomas' NHS Foundation Trust, personal communication, 23 July 2013).

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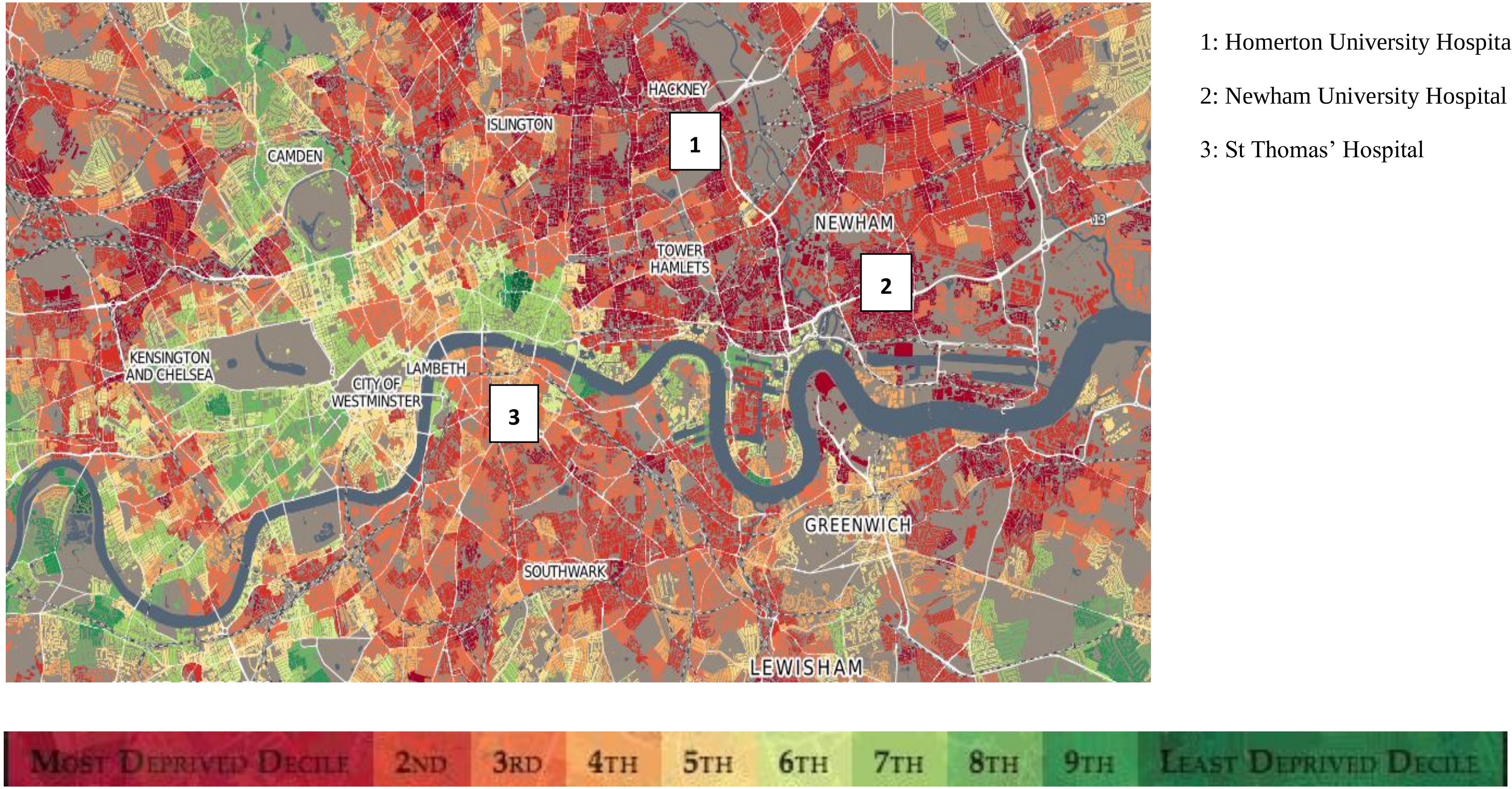
[105] As measured by multiple indices of deprivation which combine a number of indicators pertaining to economic, social and housing issues (see https://www.gov.uk/government/organisations/department-for-communities-and-local-government/series/english-indices-of-deprivation, accessed 17 July 2013).

[106] People who are not "ordinarily resident" in the UK (which includes those without secure immigration status) are liable to be charged for healthcare apart from that which is deemed immediately necessary and treatment of communicable diseases (Department of Health 2011).

[107] Data obtained from http://www.homerton.nhs.uk/our-services/sexual-health/csshh-centre-for-the-stud11731067065572/ (accessed 17 July 2013).

Figure 3.4: Multiple deprivation indices mapped onto London with study recruitment sites



1: Homerton University Hospital

2: Newham University Hospital

3: St Thomas’ Hospital

Source: http://casa.oobrien.com/booth/ (accessed 18 July 2013).

Specialist HIV antenatal clinics were held once a week at each centre, although they operated differently in each site. In one hospital the HIV specialist doctor and midwife, together with the obstetrician, ran a clinic at the same time and shared patients between them. In other centres, the HIV specialist doctor saw the patient separately within the hospital's HIV department, with women attending the main antenatal department for their antenatal care. Each of the three centres had a dedicated HIV antenatal multidisciplinary team comprising an HIV specialist doctor (with an interest in HIV and pregnancy), an HIV specialist midwife and a paediatrician. Two of the teams had an obstetrician with a specialist interest in HIV. One team also included a social welfare advisor to provide patients with support around housing, finance and immigration.

I interviewed twenty-four women during the course of my fieldwork, of whom all but one were recruited from these three NHS sites[108]. Their ages ranged from 26 to 41years (median 34 years). They came from twelve countries in Africa and had been in the UK from a few months up to 20 years (median 7.5 years); with thirteen having secure immigration status. The majority had come to study or for work but five had fled political persecution. Over half had been educated to degree level and all but one spoke English as a first or second language. Ten of the twenty-four women were unemployed when I interviewed them and five described poor quality or temporary housing. Fifteen were in relationships at the time with five describing recent experiences of intimate partner violence[109]. The vast majority described themselves as religious, mainly Christian with ten describing themselves as Pentecostal.

The subject of faith, especially Pentecostalism was a recurrent theme in interviews with women and was cited as a barrier to accessing care by healthcare and charity professionals. This prompted me to conduct a six-week period of participant observation at the Triumph of Christ Pentecostal Ministry (TCPM)[110], a Pentecostal church on the outskirts of London. I specifically chose to attend TCPM as it had been mentioned in interviews by a number of women and I describe the church in greater detail in Chapter Six.

Finally, I spent a total of twenty months volunteering at Body & Soul, an award-winning London-based charity that has been supporting children and families affected

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[108] See Appendix v for participant characteristics.

[109] Defined as the physical, sexual, or psychological harm by a current or former partner or spouse. See http://www.who.int/violence_injury_prevention/violence/world_report/factsheets/en/ipvfacts.pdf , accessed 17 July 2013).

[110] I refer to the church by a pseudonym throughout this thesis.

by HIV since 1996[111]. It provides workshops, peer support, one-to-one support, and counselling and alternative therapies to over 150 members, mainly from London but also from other parts of the UK, in a purpose-built site in central London.

3.4.3 Situating myself in my field

My ethnographic field is the city in which I have lived for nearly fourteen years, all of that time in Hackney in East London, close to one of my collaborating NHS sites. I have also worked as doctor since 1999. Ten of those years have been spent working in the field of HIV and Sexual Health, mainly in East London. During my fieldwork I continued to work as an HIV clinician at one of the sites where I was conducting my research (Homerton University Hospital). I therefore entered the field with personal experience of living in East London and significant professional experience of working with people living with HIV, primarily African migrant women. With regards to my fieldwork in NHS sites this was an asset. It gave me in-depth knowledge of HIV and pregnancy, a familiarity with the language and set-up of the clinics, and a wide range of professional networks to draw upon during the study. On the other hand I may have overlooked some aspects of HIV and pregnancy, given my familiarity with clinical services and settings.

On a personal level, I am a thirty-seven year old second-generation UK-born Asian female doctor who has never had children, conducting research with first-generation African HIV-positive migrant mothers, many of whom faced significant social and economic hardship. Within the statement above are similarities and differences, which I have endeavoured to keep in mind throughout the research process.

3.4.4 Semi-structured interviews

Interviews are ubiquitous not only in qualitative research but also in contemporary society (Atkinson et al. 1997) and are accepted as a natural and effective method of gaining knowledge. It is important to critically engage with interviewing as a method in itself and challenge the assumption that “what is said is […] a reflection of what is ‘out there’ rather than […] an interpretation which is jointly produced by interviewer and respondent” (Briggs 1986: 3). The presupposition that interviews are a neutral method capable of capturing a direct representation of experience fails to account for the fact

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[111] Further information about Body & Soul is available on their website at http://www.bodyandsoulcharity.org/.

that what is produced in an interview is an *account* of the respondent's experience. Interviews are a "speech event" (Ibid:2), subjected to "communicative ideologies" (Briggs 2007) in terms of communicative norms and the intended audience. Furthermore, accounts are shifting and context dependent and sometimes not immediately accessible to the respondent themselves. These accounts are dialogic, constructed by interviewer and respondent, and are therefore shaped by power and interest on both sides.

Whilst it is important to acknowledge the epistemological challenges presented by interviews, they remain an important and useful entry point into people's experiences, and were a key method by which I collected data on women's experiences during and after pregnancy[112].

Between October 2010 and October 2011 I interviewed twenty-four African women living with HIV. All but one were pregnant at the time I first interviewed them[113]. Almost all women were recruited from three specialist NHS HIV antenatal clinics in London[114]. I conducted initial face-to-face interviews (nineteen) in a private room in the hospital site with an interpreter present if required[115]. Topics covered included experiences of pregnancy; attitudes towards medical interventions; experiences of healthcare during pregnancy; and stigma and discrimination[116]. The interview framework was open-ended allowing for new topics to emerge during conversations and over the course my fieldwork. I arranged follow-up interviews after birth with the twenty-three women whom I had interviewed during pregnancy, of whom fourteen were interviewed postnatally[117]. The follow-up interview occurred at a convenient time for my participants, up to one year after delivery, although I was unable to contact some women and others declined (figure 3.5). Topics included experiences of delivery; experiences of infant feeding; support at home after delivery; and engagement with HIV

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[112] In my use of interviews as a predominant method of data collection I have been influenced by the work of Emily Martin on Baltimore women's understanding of reproductive processes (1987) and Linda Blum on breastfeeding in North America (1999).

[113] I approached one woman whilst pregnant but she chose to defer her interview until after delivery due to poor health towards the end of her pregnancy.

[114] One interview was conducted with a woman I met whilst volunteering at an HIV charity.

[115] One initial interview was conducted at a participant's house. Only one interview was conducted with an interpreter.

[116] See Appendix vi for the interview guide.

[117] Serial interviews can result in the development of increased trust between researcher and participant, facilitating more open discussion (Murray, et al. 2009). Furthermore, given that the transition between pregnancy and motherhood is a dynamic time, I felt that serial interviews might better capture this changing experience (Ibid.).

services after delivery[118].

I conducted four of the initial interviews by telephone when women stated a preference for this. Six of the postnatal interviews were also conducted by telephone due to women's difficulty in attending for an interview when caring for a newborn infant. The pre-eminence of face-to-face interaction in anthropological fieldwork has been challenged as other modes of communication such as mobile phones have become integral to contemporary life (Sunderland 1999). Whilst useful in engaging hard to reach groups such as mothers with young children (Musselwhite et al. 2007), telephone interviewing brings its own challenges such as maintaining respondent involvement, understanding accents, not having access to non-verbal communication and encountering difficult disclosures. However, on balance I found very little difference in the accounts produced by telephone and face-to-face. All face-to-face and telephone interviews were recorded on a digital voice recorder where possible, except for when a woman felt uncomfortable with this. In these two cases, I took extensive contemporaneous written notes.

I wanted to reflect a breadth of experience of pregnancy in the context of HIV and therefore attempted to recruit women from a range of African countries who had been in the UK for varying lengths of time. This allowed me to compare experiences across groups. I also included women who had been diagnosed before and during their current pregnancy. Some of my sampling was guided by initial quantitative results in order to explore emerging findings[119].

For interviews conducted within NHS clinics, I asked healthcare professionals to identify and approach African women attending for HIV antenatal care who might be suitable for the study. I based myself on site when the HIV antenatal clinics were running in order to be available to discuss the project further and provide women who were interested with an information sheet[120]. If a woman wished to participate we found a convenient time for her to come back to the hospital to be interviewed, before which I obtained written informed consent[121].

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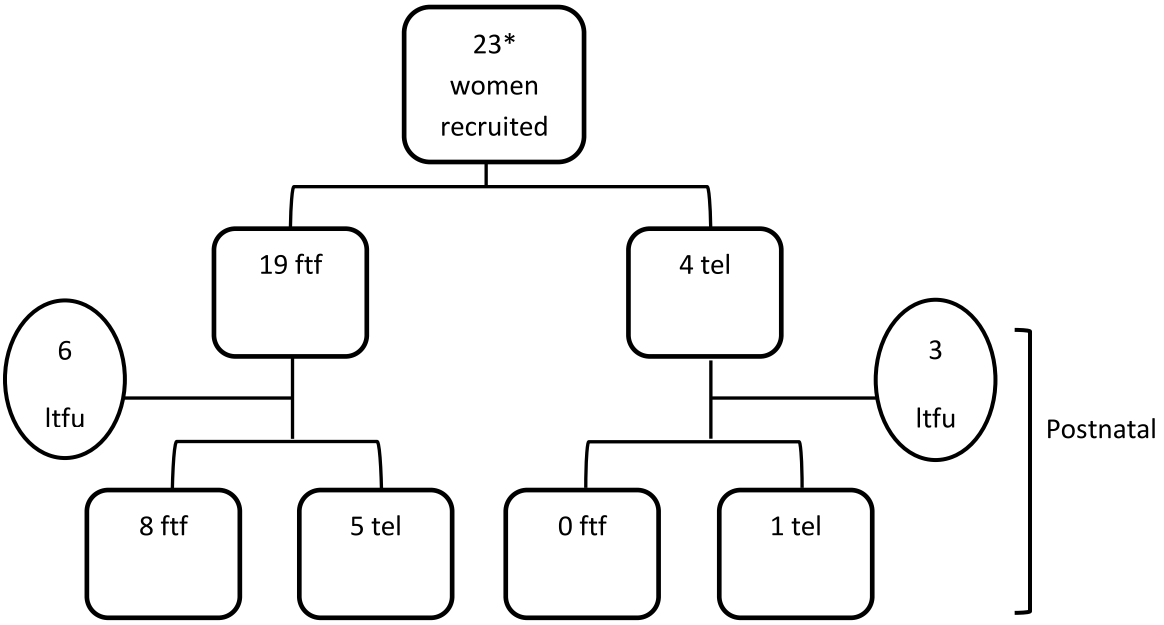
[118] See Appendix vi for the interview guide.

[119] For example, the quantitative analysis revealed that Western African women were less likely to receive ART during pregnancy and I therefore sought to interview greater numbers of women from Western African countries to explore this in greater detail.

[120] See Appendix vii for an example of a participant information sheet.

[121] See Appendix viii for an example of a participant consent form.

Figure 3.5: Recruitment and follow-up of interview participants



* 1 woman was recruited and interviewed postnatally face-to-face
ftf, face-to-face interview; tel, telephone interview; ltfu, lost to follow-up

I also conducted interviews with four healthcare professionals involved in the care of pregnant women living with HIV at the collaborating NHS clinics. They comprised two consultants in HIV medicine, one HIV specialist midwife and one specialist nurse in genitourinary medicine. Interviews were also conducted with two professionals from voluntary sector organisations with experience of supporting African women living with HIV. These participants were identified through my knowledge of local voluntary sector organisations and professional networks. The purpose of interviewing health care and charity professionals was to elicit their experience of providing care to this group of women and to identify what they saw as barriers to accessing care. In total I conducted forty-four interviews with HIV-positive African women and professionals working with them, over a fourteen-month period between 2010 and 2011.

In her 1987 ethnography of the cultural representation of reproduction in the United States, Emily Martin acknowledges that interview-based studies sometimes forego “the rich, multi-layered texture of life” that is experienced through traditional modes of fieldwork (1987: 9). Furthermore, my interviews occurred mainly in clinical spaces filled with medical paraphernalia and were conducted primarily in English[122]. Like Martin (Ibid.), I have attempted to address this potential lack of depth by immersing myself in my field as fully as possible. During my fieldwork I continued to work as an HIV clinician in one of the collaborating clinics and as a volunteer at an HIV charity, keeping a record of my observations and informal exchanges with colleagues in order to inform my analysis.

3.4.5 Participant observation

I undertook participant observation in three different sites during the qualitative phase of this study.

Antenatal clinics

Firstly, I conducted ad-hoc participant observation in the HIV antenatal clinics I collaborated with, one of which was based in the hospital in which I continued to work as an HIV clinician. This mainly comprised observing and reflecting upon consultations (including some of my own) and conversations with clinical colleagues. In two of the clinics I worked with I was also invited to attend the pre-clinic meeting where patients and management plans were discussed at length within the multidisciplinary team. I recorded my thoughts and observations as written field notes, and although they do not appear in this thesis (to preserve confidentiality) they were integral in shaping my understanding of the research question.

Body and Soul

I also volunteered at an HIV charity (Body & Soul) between April 2010 and December 2011. During this time I worked with the "Adults' Group", assisting with serving food and coordinating the running of group sessions. There were very few pregnant women attending the service during the study period and it was not feasible to engage people in lengthy conversations as they were often attending for specific meetings or workshops. Despite these limitations, volunteering at Body & Soul gave me important insights into the lives of HIV-positive people and how HIV was discussed outside of a clinical environment. It has also been invaluable in forging networks to disseminate my work to people living with HIV and gain feedback on my findings. I recorded my thoughts

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[122] All women were offered the use of an interpreting service however all but one preferred to conduct the interview in English (many stating that this was their first language). However, I am conscious that for some women certain cultural concepts may not have been easily translatable into English.

and observations as written field notes immediately after a session ended. Again, although very little data from my fieldwork at Body & Soul appear formally in this thesis, my thinking about HIV in the lives of African migrants has been shaped by my observations and experiences there.

Pentecostal church

The most consolidated period of ethnographic fieldwork I undertook in the course of this research was between July and September 2011, when I conducted nearly forty hours of participant observation in the Triumph of Christ Pentecostal Ministry. Over the course of six weeks, I attended daily church services including one all night prayer vigil, keeping extensive written field notes and voice memos on a digital voice recorder. This was complemented by watching footage of TCPM church services broadcast on satellite television, and conducting in-depth audio-recorded interviews with two members[123] of the congregation and a local pastor (who also worked as a specialist nurse in genitourinary medicine) who was familiar with the church.

This period of fieldwork was brief by necessity given the time constraints of a three-year mixed-methods PhD and has particular limitations when compared with the prolonged periods of immersion typical of most anthropological research[124]. A longer period of ethnographic fieldwork would have resulted in a deeper understanding of the church and increased access to members of the congregation and clergy. The brevity of the fieldwork was a necessary compromise. However it remains useful and has generated important insights into the interaction between Pentecostal faith and HIV in the daily lives of African migrants in the UK.

3.4.6 Analysis of qualitative data

I employed a professional transcription company to transcribe all interviews, and I quality checked a proportion of transcriptions throughout the qualitative phase to ensure accuracy. I used the Qualitative Data Analysis (QDA) software NVivo 9.0 (QSR International Pty Ltd., 2010) to manage interview data. QDA software allows the storage, classifying, sorting and linking of data, which can improve efficiency and efficacy in analysis (Bazeley et al. 2013), however it is important to note that it does not

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[123] Both of these interviews were recorded on a digital voice recorder having gained written informed consent from participants and then transcribed verbatim.

[124] Traditional views of ethnographic research requiring extended periods of time in the field have been challenged as the role of innovative and pragmatic approaches such as brief ethnography has become increasingly recognised (Green, et al. 2009).

have any analytical function itself. I undertook a thematic analysis of interview data, using the constant comparative method usually associated with grounded theory (Pope et al. 2000). This is an inductive process where each transcript is read several times and sections of the text coded within the database. Coded text are then compared and linked across all the interviews if they capture a similar theme, leading to the development of broader key categories. I paid particular attention to the context of coded text by reading transcripts in their entirety several times, rather than focusing on small sections of coded text in isolation. I also sought out data, which did not appear to fit into the emerging thematic framework, in order to deepen my understanding. As well as these inductive codes, I devised some *a priori* codes from the quantitative phase of the study, allowing me to interrogate the qualitative data to generate insights into my quantitative findings.

I made extensive written field notes during ethnographic fieldwork conducted at both Body & Soul and the Pentecostal church. I hand-coded these field notes rather than transcribing them and entering them into NVivo as this was time efficient. I used a manual index system to organise this data. I began with open coding, a process where codes are identified from the data without restriction, later developing broader thematic categories using the constant comparative method described above.

Throughout the qualitative phase I discussed the interpretation of my data with other anthropological colleagues, including one of my supervisors, and several doctoral and post-doctoral students with ethnographic experience of either Pentecostalism in London or HIV and pregnancy. I also presented my emergent findings to colleagues in HIV departments and patient groups. This allowed me to receive feedback on my analysis and also gave me increased confidence in my interpretation of the data.

3.4.7 Ethical considerations

The qualitative phase of the study has ethical approval from City University Research Ethics Committee for qualitative research conducted outside NHS sites (ref PhD/09-10/10)[125]. It also has approval from the West London Research Ethics Committee for the overall qualitative phase, including research conducted with NHS staff and patients (ref 10/10707/49)[126].

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[125] See Appendix ix for ethical approval from City University Ethics Committee.

[126] See Appendix x for ethical approval from the West London Research Ethics Committee on behalf of NHS sites.

I obtained written consent from all participants I interviewed and ensured that I revisited this in subsequent interviews. I emphasised to women recruited through NHS clinics that participation was independent of any care received and that declining to be interviewed would have no negative repercussions. I did not approach any woman I have looked after in a clinical capacity. I have given pseudonyms to all my participants in this thesis[127] and omitted or changed details that may render them identifiable.

I also obtained written consent from Body & Soul on behalf of their members and regularly ensured that members were aware of my presence as a researcher. I was unable to secure written consent from the Pentecostal Church for participation observation. I was not able to arrange a meeting with the senior Pastor and assistant pastors were unwilling to consent on his behalf[128]. The church clergy were aware of my presence at services as a researcher exploring health and healing within the church[129] and were provided with an information sheet[130]. As I was not asked to leave I assumed assent and instead sought written consent from individual church members before conducting interviews. After discussion with City University's research ethics committee, I present findings from this part of my fieldwork in this thesis with identifiable data omitted or changed to protect the identity of the church and those within it.

3.4.8 Conclusions

The overarching question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? Answering this question involves engaging with clinical outcomes, access to services, beliefs and lived experiences. To achieve an understanding of the multidimensional nature of the pregnancy in the context of HIV in this group of women I have used a two phase mixed methods research approach combining epidemiological and anthropological methods. In the first phase (quantitative) I analysed data on approximately 10,000 pregnancies from the National Study of Pregnancy in HIV and Childhood, the UK and Ireland's comprehensive surveillance programme for HIV in pregnancy. I also matched data from the NSHPC and another national epidemiological

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[127] I have chosen to use common names from the countries my participants were from (rather than codes or numbers) in order to preserve narrative flow.

[128] I also had concerns that, given his authority, had the pastor consented on behalf of the congregation individual church members would feel under pressure to participate.

[129] The brief nature of my fieldwork precluded discussions of sensitive topics such as HIV.

[130] See Appendix xi for examples of participant information sheets.

dataset (SOPHID) in order to explore loss to follow-up after pregnancy. In the second phase I conducted multi-sited ethnographic fieldwork in London to explore HIV-positive migrant African women's experiences of pregnancy and early motherhood. My methods mainly comprised semi-structured interviews with twenty-four pregnant African women living with HIV (and those involved in their care), and participant observation in a number of sites including a Pentecostal church. Where possible the findings from the quantitative and qualitative analyses will be presented and interpreted together in this thesis to achieve a deeper understanding of how African HIV-positive women engage with services during and after pregnancy than would be possible by drawing upon either epidemiological or ethnographic data alone.

Key Points

- The overarching research question in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? This question encompasses clinical and service-related outcomes as well as the experiences of pregnant African women living with HIV.

- A mixed methods approach (combining quantitative and qualitative methods in the same study) is suited to understanding this type of complex, multi-dimensional phenomena.

- In this thesis I use a combination of epidemiological and anthropological methods.

- In the quantitative phase I analysed data from the National Study of HIV in Pregnancy and Childhood, the UK and Ireland's comprehensive national surveillance programme for HIV in pregnancy, and from the Survey of Prevalent HIV Infections Diagnosed.

- In the qualitative phase I conducted multi-sited ethnographic research in London comprising semi-structured interviews and participant observation.

- The quantitative and qualitative datasets have been kept analytically distinct. However during analyses I have moved between the two datasets and also linked them at the interpretation stage in order to achieve integration.

4

Pregnancy and HIV in African migrant women living in the UK: epidemiological overview 1990 - 2010

Summary

In this first empirical chapter of my thesis, I draw upon NSHPC data to provide, for the first time, a broad overview of HIV and pregnancy in the UK with specific reference to African women. I present updated data on trends in ethnicity of women whose pregnancies were reported to the NHSPC between 1990 and 2010. Previous analyses of NSHPC data have not explored trends in pregnancies in African women in detail. Here I explore trends in maternal African region of birth and duration of residence in the UK, both nationally and within reporting regions, between 1990 and 2010. Finally I focus on pregnancies reported in white British and African women between 2000 and 2010, which form the basis of analyses presented in Chapters Five, Seven and Eight, presenting baseline demographic and clinical characteristics. This epidemiological overview of pregnancy in HIV-positive African women living in the UK will provide context for the presentation of quantitative and qualitative data in the subsequent chapters.

4.1 Introduction

As described in Chapter One, there have been changes in the epidemiology of HIV over the past three decades. Heterosexually acquired HIV infection has increased both worldwide and within the UK. In the UK, heterosexual Black African women now comprise the second largest group of people living with HIV, after men who have sex with men; a reflection of the global burden of disease still shouldered by Sub-Saharan African countries. In Chapter One I highlighted the sharp increase in the UK in the number of pregnancies in women with diagnosed HIV-infection, the majority being in women of Black African ethnicity (Townsend et al. 2008b). In this chapter I provide an epidemiological overview of pregnancy and HIV in the UK with specific reference to African women. I first present data on trends in maternal ethnicity, African region of birth and duration of residence in the UK at the time of conception between 1990 and

2010. I then present baseline demographic and clinical characteristics of African and white British women who were reported as pregnant between 2000 and 2010[131], as they form the basis of analyses presented in Chapter Five, Seven and Eight.

4.2 Trends over time

There were 13,676 pregnancies reported to the NSHPC in 10,141 women between 1990 and 2010. The annual number of reported pregnancies increased from 58 in 1990 to 1351 in 2010, the majority (12193/13676; 89%) reported between 2000 and 2010. Between 1990 and 2010 three quarters of pregnancies in the UK reported to the NHSPC (10,191/13,676) were in African women. The number and proportion of African women (of Black African ethnicity and born in Sub-Saharan Africa)[132] increased significantly between 1990 and 2006 (figure 4.1 and table 4.1). The number and proportion stabilised between 2007 and 2010 but African women remained by far the largest group numerically. Of note there was a significant increase in women of both Caribbean and “Other” ethnicities (comprising Asian, mixed and other ethnicities) throughout the study period (both $p_{trend}<0.001$), although their proportions remained small.

Between 1990 and 2010, 10,191 pregnancies were reported in African women. More than half (6300/10,191; 62%) were in women born in Eastern Africa[133] with Western African women the second largest group (2102/10,191; 20.6%) during this time period. Women from Southern and Middle African constituted much smaller groups at 7.3% and 10.2% respectively. Over 60% (6278) of pregnancies in African women were in women born in Zimbabwe, Uganda, Nigeria, South Africa or Zambia (table 4.2), with Zimbabwean women being the largest group of these five countries.

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[131] This time period corresponds with wider use of HAART in pregnancy and more consistency in clinical practice and laboratory monitoring than in the previous decade.

[132] Previous analyses of NSHPC data have used “Black African” as an ethnicity category without specifying place of birth. The overwhelming majority of Black African women reported to the NSHPC were born in Sub-Saharan Africa. Between 1990 and 2010, 10,634 pregnancies reported to the NSHPC were reported in Black African women, of whom 10,191 (95.8%) were born in Sub-Saharan Africa (data from the Q87 NSHPC dataset with reports up to and including June 2011.

[133] See Chapter 3 (table 3.4: 71) for definitions of United Nations geographical region categories.

Figure 4.1: Trends in maternal ethnicity in pregnancies reported to the NSHPC (proportions), 1990-2010 (n=13,676)

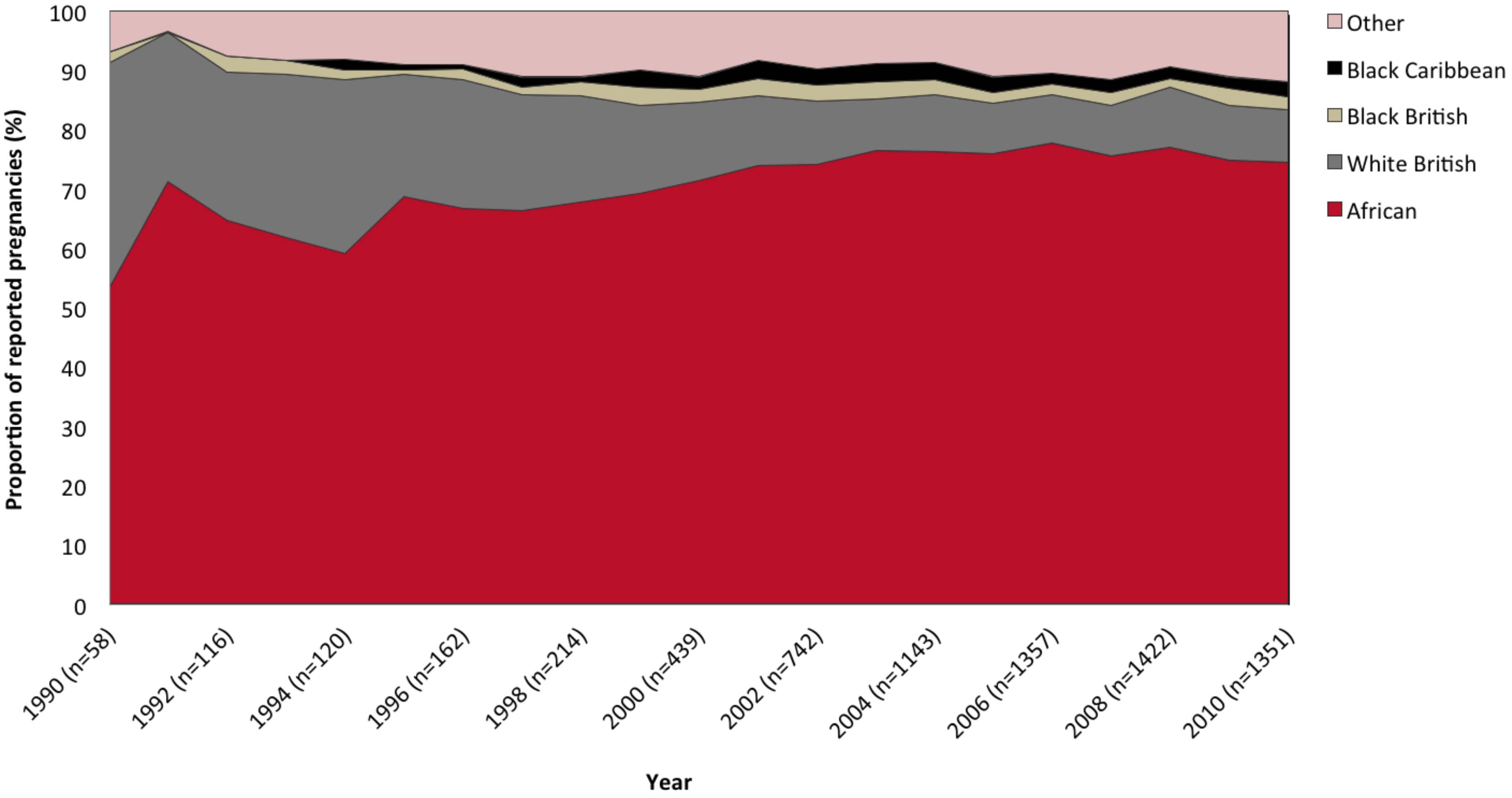


Table 4.1: Trends in maternal ethnicity in pregnancies reported to NSHPC by time period, 1990 – 2010

	Time period n (column %)							
	1990-93	**1994-96**	**1997-99**	**2000-03**	**2004-06**	**2007-10**	**Total (row)**	***p*-value*†**
White British	108 (27.8)	97 (23.5)	115 (16.9)	291 (10.6)	330 (8.70)	520 (9.2)	1461	<0.001
African	246 (63.4)	269 (65.1)	464 (68.0)	2053 (74.4)	2906 (76.6)	4253 (75.4)	12191	<0.001
Black British	7 (1.8)	6 (1.5)	16 (2.4)	76 (2.8)	76 (2.0)	121 (2.2)	302	0.817
Black Caribbean	0 (0.0)	4 (1.0)	14 (2.1)	78 (2.8)	95 (2.5)	121 (2.1)	307	<0.001
Other	27 (7.0)	37 (9.0)	73 (11.9)	260 (9.4)	387 (10.2)	626 (11.1)	1409	0.003
Total (column)	**388**	**413**	**682**	**2758**	**3794**	**5641**	**13676**	

**p*-value for trend over time for each category compared with others combined using logistic regression. †All significance levels with α=0.05 set at $p<0.01$ (Bonferroni correction).

Table 4.2: Maternal country of birth in pregnancies reported to NSHPC, 1990-2010 (restricted to the ten African countries contributing the greatest number of pregnancies, n=8175)

Country	Number of pregnancies (%)
Zimbabwe	2811 (34.4)
Uganda	1227 (15.0)
Nigeria	1070 (13.1)
South Africa	645 (7.9)
Zambia	525 (6.4)
Ghana	473 (5.8)
Congo	437 (5.3)
Malawi	358 (4.4)
Kenya	349 (4.3)
Cameroon	280 (3.4)

The number of reported pregnancies increased over time in women from all African regions (table 4.3). Women from Eastern Africa remained the largest group throughout the study period but the proportion of pregnancies reported in women from this region significantly decreased from 87.1% (27/31) in 1990 to 62.0% (623/1005) in 2010 ($p_{trend}<0.001$, figure 4.2). The number of women from Southern Africa (almost entirely South African) increased from 1 (0.4%) to 65 (6.5%) during this period ($p_{trend}<0.001$, figure 4.2), as did the number of women from Middle Africa (from 3 in 1990 to 82 in 2010, $p_{trend}<0.001$, figure 4.2). However, the most striking change was in the number of pregnancies reported in Western African women from only one reported pregnancy in 1990 (3.2%) to 235 (23.4%) in 2010 ($p_{trend}<0.001$, figure 4.2).

Over 60% of pregnancies in African women were in women born in Zimbabwe, Uganda, Nigeria, South Africa and Zambia (table 4.2). Numbers of pregnancies in women born in each of these five countries increased between 1990 and 2010. However the proportions have changed over time with a predominance of Ugandan women earlier in the time period and an increasing proportion of Zimbabwean, and to a lesser extent Nigerian, women from the late 1990s onwards (figure 4.3).

Table 4.3: Trends in maternal African region of birth in pregnancies reported to NSHPC by time period, 1990 – 2010

	Time period n (column %)							
	1990-93	**1994-96**	**1997-99**	**2000-03**	**2004-06**	**2007-10**	**Total (row)**	***p*-value*†**
Eastern African	215 (87.4)	200 (74.4)	323 (69.6)	1287 (62.7)	1709 (58.8)	2566 (60.3)	6300	<0.001
Southern African	1 (0.4)	2 (0.7)	12 (2.6)	145 (7.1)	259 (8.9)	329 (7.7)	748	<0.001
Western African	13 (5.3)	30 (11.2)	71 (15.3)	369 (18.0)	629 (21.6)	990 (23.3)	2102	0.817
Middle African	17 (6.9)	37 (13.8)	58 (12.5)	252 (12.3)	309 (10.6)	368 (8.7)	1041	<0.001
Total (column)	**246**	**269**	**464**	**2053**	**2906**	**4253**	**10191**	

**p*-value for trend over time for each category compared with others combined using logistic regression. †All significance levels with α=0.05 set at *p*<0.01 (Bonferroni correction).

Figure 4.2: Trends in maternal African region of birth in pregnancies reported to the NSHPC (numbers), 1990-2010

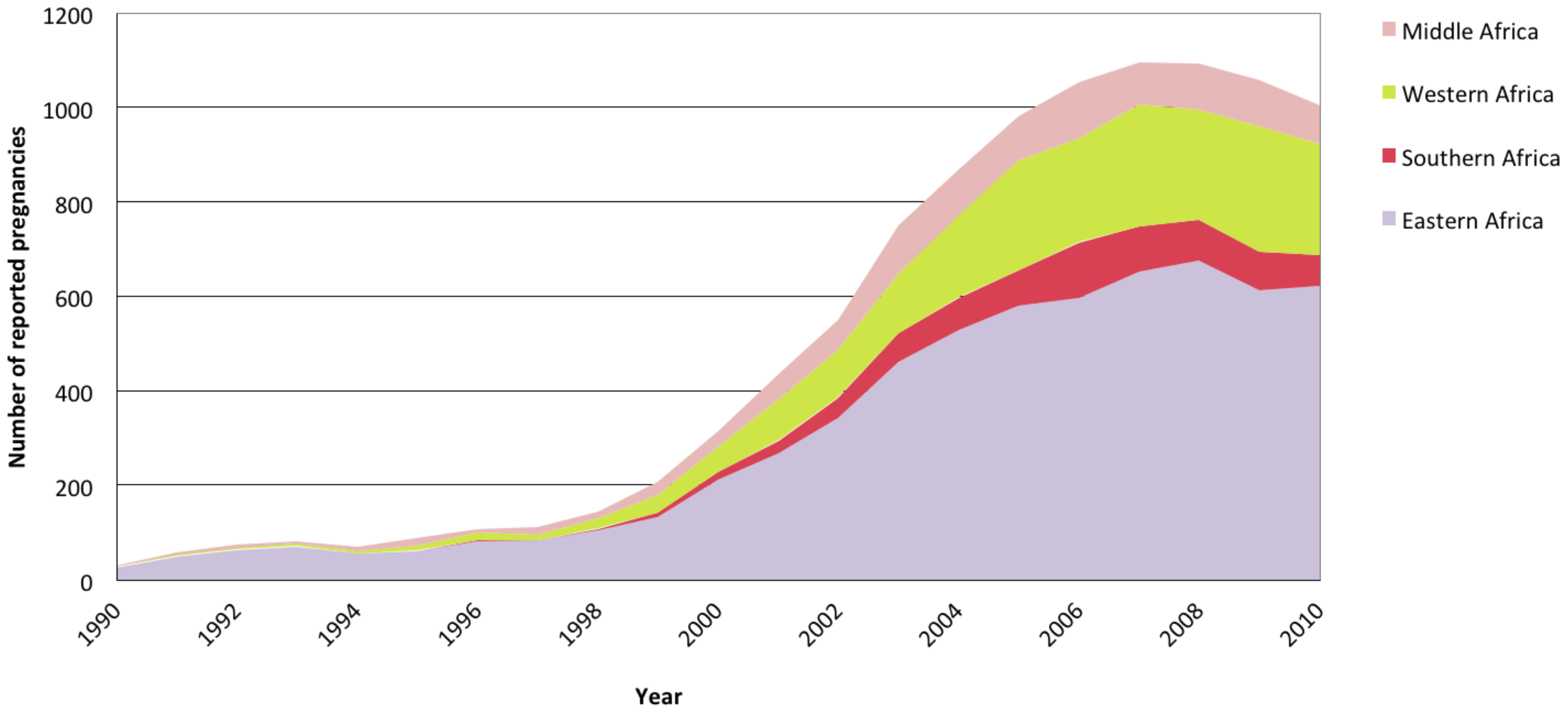
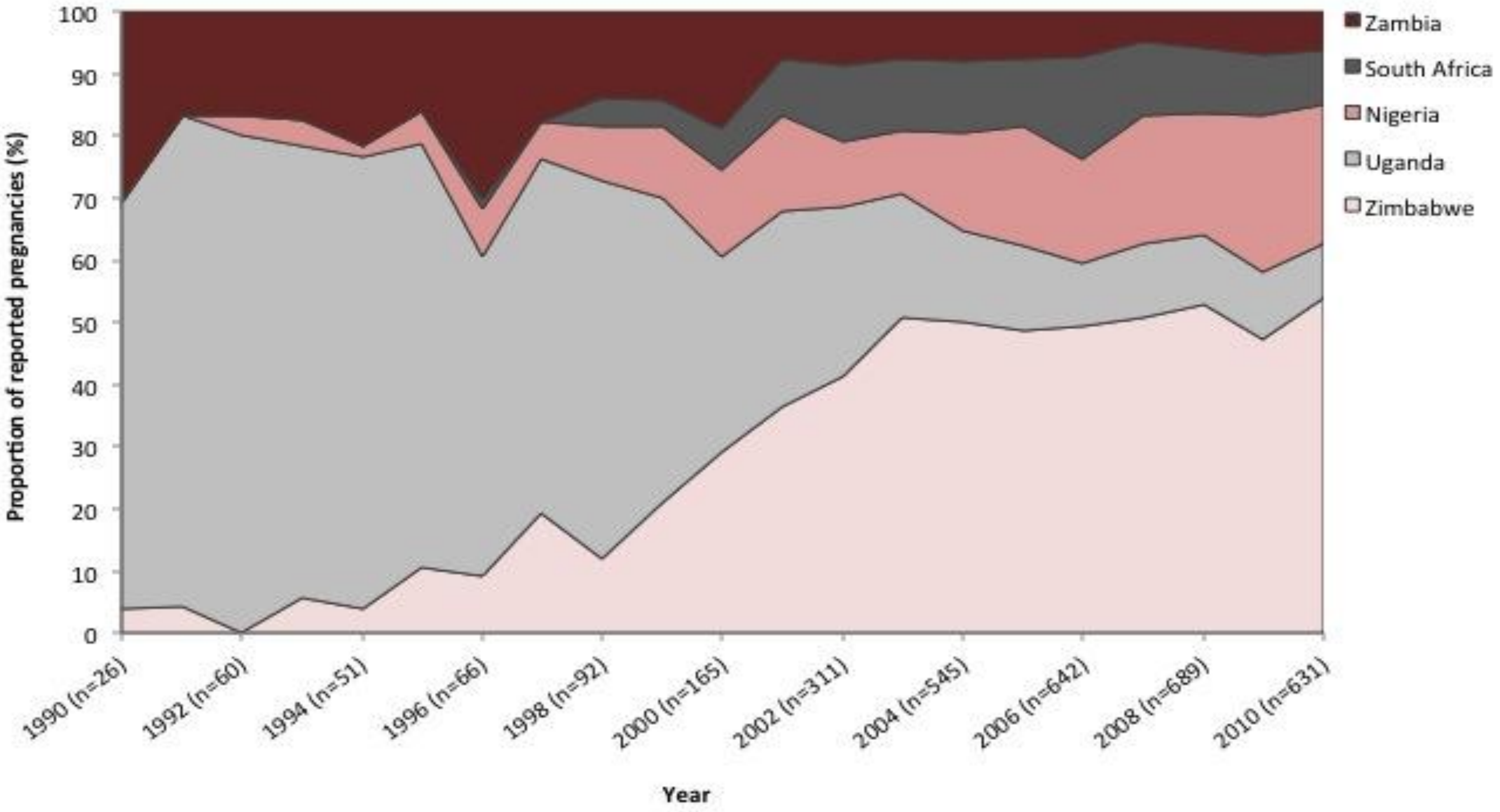


Figure 4.3: Trends in maternal African country of birth in pregnancies reported to the NSHPC (proportions), 1990-2010 (restricted to top five countries, n=6278)



Duration of residence in the UK was measured from the mother's documented date of arrival in the UK to estimated date of conception of the reported pregnancy. Analyses were restricted to first pregnancies reported to the NSHPC in African women[134]. Date of arrival in the UK was not reported in 3023 (40.0%) pregnancies[135]; therefore the following analysis is based on 4543 pregnancies.

The median duration of residence in the UK at conception of first reported pregnancy to the NSHPC for African women was 2.9 years (interquartile range [IQR]: 0.8, 5.7 years). Of the 575 pregnancies in women who had arrived in the UK after conception, only a small proportion (12.9%) were in women known to have been diagnosed with HIV prior to the reported pregnancy. Median duration of residence varied across African regional groups as shown in table 4.4 (p Kruskal-Wallis<0.001, table 4.4), with women from Eastern Africa having resided in the UK the longest and those from Middle African the shortest period of time. Among all African women, the median maternal duration of residence in the UK at time of conception increased from 2.3 years (IQR: 2.3, 2.5 years) in 1990 to 6.3 years (IQR: 2.3, 8.7 years) in 2010, with a sharp decrease in 1999 but a steady increase from 2002 onwards (figure 4.4)[136].

Table 4.4: Duration of residence in the UK at conception by maternal African region of birth

Maternal African region of birth	Median duration of residence in the UK in years*
Eastern Africa	3.5 (IQR: 1.3, 6.1)
Southern Africa	1.8 (IQR: 0.4, 4.0)
Western Africa	2.4 (IQR: 0.4, 5.2)
Middle Africa	1.6 (IQR: 0.1, 4.8)

IQR, interquartile range; * $p_{Kruskal\text{-}Wallis}$<0.001

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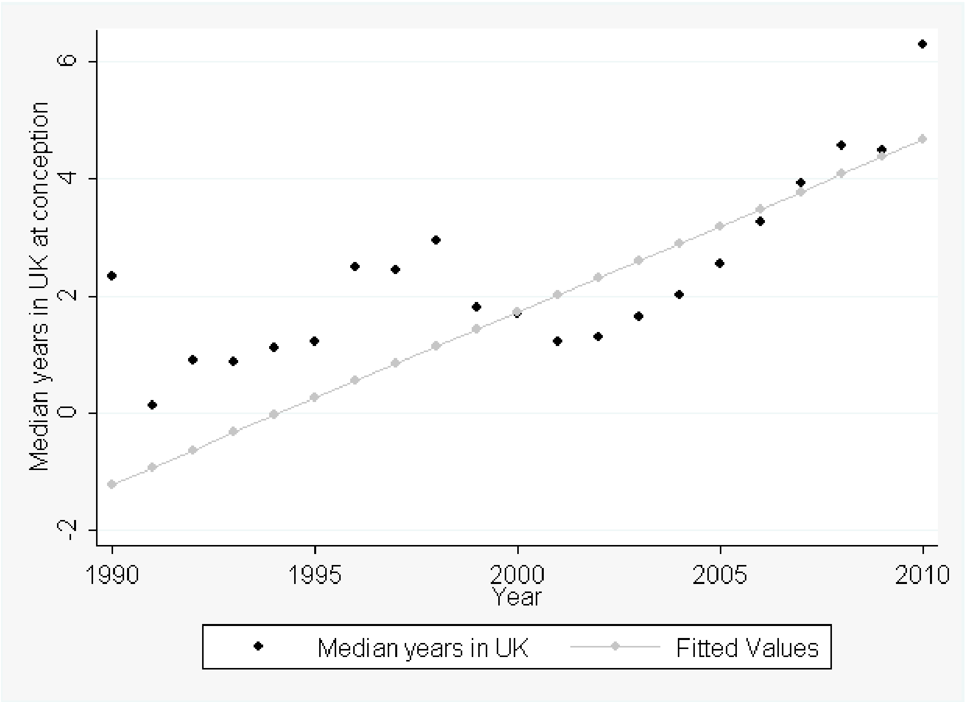
[134] Sequential pregnancies were not included as duration of residence would be correlated with time between pregnancies and would partly be a measure of this.

[135] Missing data on maternal duration of residence in the UK is discussed in Chapter Three (73-74).

[136] It is important to be aware that the proportion of data missing on maternal duration of residence in the UK reached up to 95% in some of the years preceding 2000 which means estimates earlier in the study period are likely to be less reliable. All analyses using maternal duration of residence in the UK presented in this thesis are restricted to pregnancies reported between 2000 and 2010 when the proportion of missing data was consistently below 45%.

Figure 4.4: Median maternal duration of residence in the UK or Ireland at time of conception for African women (restricted to first reported pregnancy to NSHPC), 1990-2010



$p<0.001$
$R^2=0.66$

4.3 Trends by geographical reporting area

Between 1990 and 2010, over half (4854/8793) of pregnancies in African women were reported by London centres[137]. However, a substantial number (3664; 41.7%) of reports came from the rest of England (table 4.5). Wales, Scotland and Northern Ireland reported the smallest number of pregnancies in African women, with white women predominating in these areas. There was variation among reporting areas with regards to maternal African region of birth as shown in table 4.5. London reported the greatest number of pregnancies in women from Western, Middle and Eastern Africa, although a large number of pregnancy reports in Eastern African women originated from the rest of England. English centres (not including London) also reported the largest number of pregnancies in Southern African women (368; 59.2%), although substantial numbers were also reported by centres in London. There were differences in duration of residence at the time of conception for African women across the UK as summarised in table 4.5, with women whose pregnancies were reported by London centres having been in the country longer than those reported by centres in Wales, Scotland and Northern

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[137] Due to small numbers of reports in women from other ethnicities this analysis is restricted to women of white British and African ethnicity.

Ireland.

Between 1990 and 2010 there were also changes in the maternal ethnic composition of pregnancies reported to the NSHPC within each reporting area (Figure 4.5). London saw a rise in reports in African women from the early 1990s, with the sharpest increase between 2000 and 2003. The rest of England also reported an increasing number of pregnancies in African women, mainly between 2000 and 2010. Wales, Scotland and Northern Ireland has seen a similar pattern but on a much smaller scale, with reports of pregnancies in African women outnumbering those in white British women for the first time in recent years.

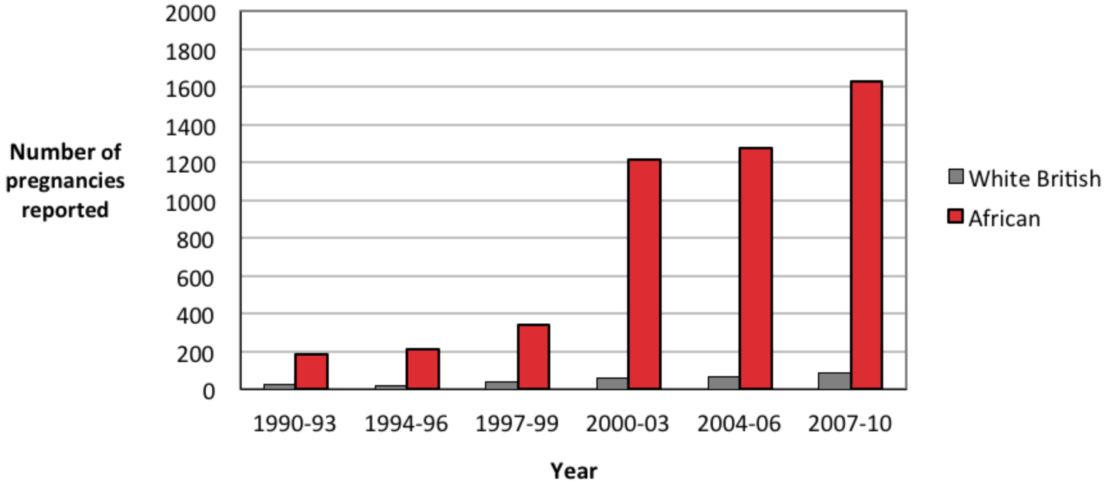
Table 4.5: Maternal ethnicity, African region of birth and maternal duration of residence in the UK at conception, by geographical reporting area in the UK, 1990-2010

	Reporting region n (column%)				
	London	**England (non-London)**	**Wales, Scotland and Northern Ireland**	**Total**	***p*-value**
Ethnicity (n=10033)					
White British	287 (5.6)	668 (15.4)	285 (50.9)	1240	
African	4854 (94.4)	3664 (84.6)	275 (49.1)	8793	<0.001*
Total	5141	4332	560		
African region of birth (n=8793)					
Eastern Africa	2682 (55.3)	2589 (70.7)	170 (61.2)	5441	
Southern Africa	218 (4.5)	368 (10.0)	36 (13.1)	622	
Western Africa	1416 (29.2)	365 (10.0)	45 (16.4)	1826	
Middle Africa	538 (11.1)	342 (9.3)	24 (8.7)	904	<0.001*
Total	4854	3664	275	8793	
Median duration of residence in the UK (years)	3.4 (IQR: 1.0, 6.5)	2.4 (IQR: 0.6, 4.8)	1.4 (IQR: 0.1, 4.1)		<0.001¶

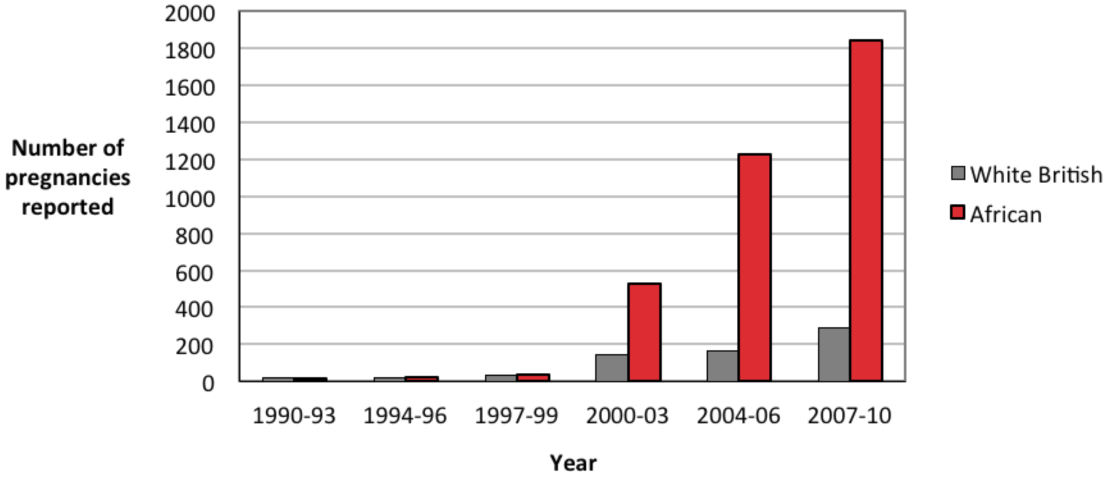
IQR, interquartile range; **p*-value obtained using χ^2test; ¶*p*-value obtained using Kruskal-Wallis test.

Figure 4.5: Maternal ethnicity in pregnancies reported to NSHPC by geographical reporting area, 2000-2010

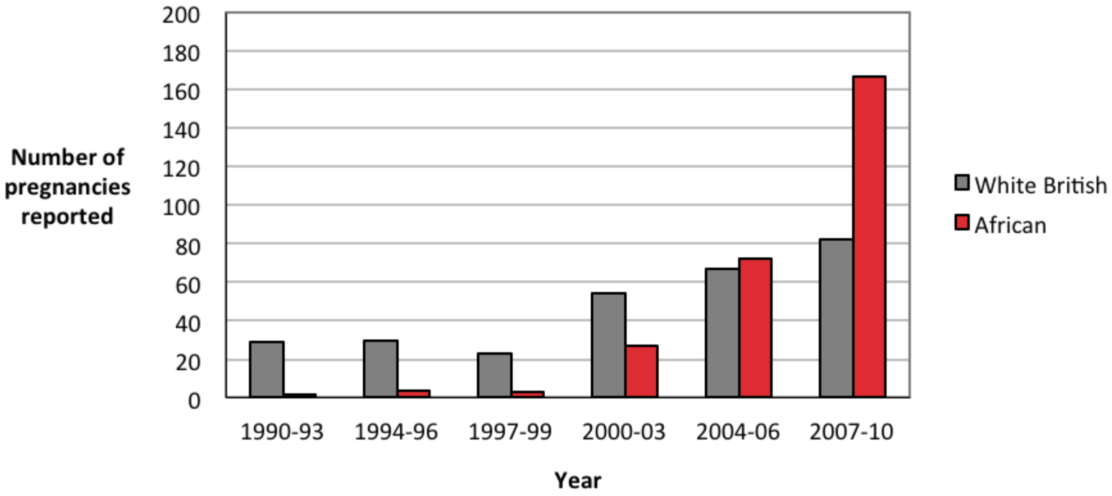
a) London



b) England (outside London)



c) Wales, Scotland and Northern Ireland*



*Note that y-axis scale is ten-fold lower than in figures 4.5a and 4.5b.

4.4 Baseline characteristics of pregnancies reported to NSHPC 2000-2010

I will now focus on pregnancies reported to the NSHPC between 2000 and 2010 in women of white British or African ethnicity who were diagnosed with HIV prior to the end of their pregnancy, as they form the basis of all subsequent quantitative analyses in this thesis. This time period corresponds with wider use of highly active antiretroviral therapy (HAART) in pregnancy and more consistency in clinical practice and laboratory monitoring than in the previous decade. As highlighted earlier in this chapter, this is also when the majority of pregnancies were reported to the NSHPC (12193/13676; 89%).

There were 10,100 pregnancies reported to the NSHPC in 7657 women between 2000 and 2010, including 175 twin or triplet pregnancies. Since 2000 there were 8626 live births, 93 stillbirths, 531 miscarriages and 339 terminations of pregnancy[138]. Data on pregnancy outcome were not available for 176 continuing pregnancies at the time of analysis. Less than 1% of pregnancies were in women infected with HIV-2 virus (33/9865)[139].

Approximately 1% (94/10,100) of pregnancies were in women who were reported to have acquired HIV through injecting drug use (table 4.6). The median maternal age at delivery was 31.2 years (IQR: 27.4, 35.0 years). In over 90% (9137/9761) of pregnancies, women received ART during pregnancy; with the majority (8189/9658; 85%) receiving HAART[140]. Comparing pregnancies in white British and African women (table 4.6), a greater proportion of Africans were diagnosed during pregnancy and had an initial CD4 count <200 cells/mm^3 (both $p<0.001$). A slightly higher proportion of African women had vaginal deliveries ($p<0.001$) whilst preterm delivery in this group was less common than in the white British group ($p<0.01$).

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[138] Data on termination of pregnancy and miscarriage are not accurate as they are often poorly reported by respondents to the NSHPC.

[139] Pregnancies in women with HIV-2 infection were included in all analyses.

[140] HAART being classified as a treatment combination of three or more antiretroviral agents.

Table 4.6: Baseline characteristics of pregnancies by maternal ethnicity (n=10100)

Characteristics †	Total	Ethnicity n (col %)		
		White British (n=1118)	African (n=8982)	*p*-value*
Maternal age at delivery				
<25	1313 (13.7)	325 (29.9)	988 (11.6)	<0.001
25-34	5884 (61.3)	531 (48.8)	4765 (65.0)	
≥35	2401 (25.0)	232 (21.3)	2169 (25.5)	
IDU				
No	10006 (99.1)	1027 (91.9)	8979 (100.0)	<0.001
Yes	94 (0.9)	91 (8.1)	3 (0.0)	
Timing of HIV diagnosis				
Before pregnancy	5959 (59.2)	728 (65.1)	5231 (58.5)	<0.001
During pregnancy	4107 (40.8)	390 (34.9)	3717 (41.5)	
Earliest HIV viral load¶ (copies/ml)				
Undetectable	2908 (36.6)	319 (36.3)	2589 (36.6)	0.385
50-10000	3050 (38.4)	324 (36.9)	2726 (38.6)	
≥10000	1990 (25.0)	236 (26.9)	1754 (24.6)	
Earliest CD4¶ (cells/mm^3)				
≥350	5016 (57.3)	654 (69.8)	4362 (55.8)	<0.001
200-349	2540 (29.0)	220 (23.5)	2320 (29.7)	
<200	1203 (13.7)	63 (6.7)	1140 (14.6)	
ART during pregnancy				
Yes	9137 (93.6)	1013 (93.3)	8124 (93.7)	0.638
No	624 (6.4)	73 (6.7)	551 (6.4)	
Duration of ART				
On ART at conception	2958 (35.4)	304 (32.7)	2654 (35.8)	0.017
12-40 weeks	3262 (39.1)	407 (43.7)	2855 (38.5)	
2-11 weeks	1949 (23.4)	205 (22.1)	1744 (23.5)	
<2 weeks	178 (2.1)	15 (1.6)	163 (2.2)	
Mode of delivery				
Elective CS	4398 (50.9)	572 (58.2)	3826 (49.9)	<0.001
Emergency CS	2038 (23.6)	194 (19.7)	1844 (24.1)	
Vaginal	2210 (25.6)	217 (22.1)	1993 (26.0)	
Gestational age (weeks)¶¶				
≥ 37	7404 (85.9)	806 (82.7)	6598 (86.4)	0.002
< 37	1211 (14.1)	169 (17.3)	1042 (13.6)	

† Numbers vary due to missing data. * *p*-value obtained using χ^2test. ¶ First reported value in pregnancy. ¶¶ Restricted to live and still births. Col, column; IDU, likely route of HIV acquisition was maternal injecting drug use; ART, antiretroviral therapy; CS, Caesarean Section.

Looking at the 8992 pregnancies in African women there were differences according to maternal African region of birth (table 4.7). Women from Eastern Africa were older ($p<0.001$). HIV diagnosis was more commonly made during pregnancy in pregnancies in Southern and Western African women ($p<0.001$) and therefore a greater proportion of these women were not on ART at conception and had a detectable initial viral load in pregnancy (both $p<0.001$), although the greatest proportion of pregnancies where ART was not received was in women from Middle Africa. There was no significant association between African region of birth and initial CD4 count in pregnancy ($p>0.5$).

Data were available on duration of residence in the UK at conception in 5813 of 8982 pregnancies in African women between 2000 and 2010 (table 4.8). Women who had arrived in the UK after conception were younger than those who had been in the UK for a longer period of time ($p<0.001$). Diagnosis of HIV was more commonly made during pregnancy in pregnancies in this group and consequently they were less likely to be on ART at conception. Women who had been in the UK for less than four years, including those who arrived after conception, were more likely to have a lower initial CD4 count and a detectable initial viral load than those who had been in the UK for longer (all $p<0.001$). ART was not received during pregnancy in a greater proportion of pregnancies in women who had arrived in the UK after conception ($p<0.05$), and there was a higher proportion of elective caesarean sections in this group ($p<0.001$), likely as a result of shorter duration of ART and consequent concerns around risk vertical transmission.

Table 4.7: Baseline characteristics of pregnancies by maternal African region of origin (n=8982)

Characteristics†	**Maternal African region of birth (col %)**				
	Eastern Africa	Southern Africa	Western Africa	Middle Africa	***p*-value***
Maternal age at delivery					
<25	527 (10.2)	93 (14.5)	219 (12.0)	149 (17.5)	<0.001
25-34	3203 (61.8)	435 (67.8)	1217 (66.5)	498 (58.5)	
≥35	1457 (28.1)	114 (17.8)	393 (21.5)	205 (24.1)	
Timing of HIV diagnosis					
Before pregnancy	3381 (62.7)	316 (44.2)	962 (49.5)	572 (64.0)	<0.001
During pregnancy	2014 (37.3)	399 (55.8)	982 (50.5)	322 (36.0)	
Earliest HIV viral load¶ (copies/ml)					
Undetectable	1664 (39.1)	166 (29.9)	467 (30.0)	292 (41.4)	<0.001
50-10000	1579 (37.1)	235 (42.3)	673 (43.3)	239 (33.9)	
≥10000	1010 (23.8)	154 (27.8)	415 (26.7)	175 (24.8)	
Earliest CD4¶ (cells/mm^3)					
≥500	2597 (55.1)	352 (56.7)	997 (57.9)	416 (54.2)	0.521
200-249	1413 (30.0)	183 (29.5)	489 (28.4)	235 (30.6)	
<200	701 (14.9)	86 (13.9)	236 (13.7)	117 (15.2)	
ART during pregnancy					
Yes	4939 (94.2)	641 (93.6)	1741 (92.7)	803 (92.3)	0.039
No	303 (5.8)	44 (6.4)	137 (7.3)	67 (7.7)	

Table 4.7: Baseline characteristics of pregnancies by maternal African region of origin continued

Characteristics†	**Maternal African region of birth (col %)**				
	Eastern Africa	Southern Africa	Western Africa	Middle Africa	***p*-value***
Duration of ART					
Before conception	1787 (39.5)	152 (26.8)	432 (26.9)	283 (39.2)	<0.001
12-40 weeks	1676 (37.1)	243 (42.9)	687 (42.8)	249 (34.5)	
2-11 weeks	970 (21.5)	164 (28.9)	437 (27.2)	173 (24.0)	
<2 weeks	88 (2.0)	8 (1.4)	50 (3.1)	17 (2.4)	
Mode of delivery					
Elective CS	2395 (51.6)	305 (51.7)	773 (46.4)	353 (46.2)	<0.001
Emergency CS	1053 (22.7)	137 (23.2)	462 (27.7)	192 (25.1)	
Vaginal	1194 (25.7)	148 (25.1)	432 (25.9)	219 (28.7)	
Gestational age (weeks)¶¶					
≥ 37	4001 (86.6)	508 (86.0)	1438 (86.2)	651 (85.9)	0.930
<37	621 (13.4)	83 (14.0)	231 (13.8)	107(14.1)	

† Numbers vary due to missing data. * *p*-value obtained using χ^2test. ¶ First reported value in pregnancy. ¶¶ Restricted to live and still births.
Col, column; ART, antiretroviral therapy; CS, Caesarean Section.

Table 4.8: Baseline characteristics of pregnancies by maternal African region of origin (n=5813)

Characteristics†	Maternal duration of residence in the UK at conception (col %)			
	≥4 years	<4 years (before conception)	Since conception	*p*-value *
Maternal age at delivery				
<25	184 (6.4)	365 (16.0)	100 (23.0)	<0.001
25-34	1655 (57.6)	1560 (68.5)	285 (65.7)	
≥35	1033 (36.0)	352 (15.5)	49 (11.3)	
Timing of HIV diagnosis				
Before pregnancy	2299 (77.2)	1113 (47.0)	66 (14.4)	<0.001
During pregnancy	680 (22.8)	1255 (53.0)	394 (85.7)	
Earliest HIV viral load (copies/ml)				
Undetectable	1134 (44.5)	573 (29.3)	68 (21.5)	<0.001
50-10000	878 (34.4)	830 (42.4)	147 (46.4)	
≥10000	538 (21.1)	553 (28.3)	102 (32.2)	
Earliest CD4 count (cells/mm^3)				
≥500	1625 (59.2)	1139 (52.5)	210 (53.2)	<0.001
200-249	776 (28.3)	681 (31.4)	118 (29.9)	
<200	344 (12.5)	349 (16.1)	67 (17.0)	
ART during pregnancy				
Yes	2763 (94.8)	2174 (93.8)	412 (91.2)	0.007
No	152 (5.2)	144 (6.2)	40 (8.9)	

Table 4.8: Baseline characteristics of pregnancies by maternal African region of origin continued

Characteristics†	Maternal duration of residence in the UK at conception (col %)			
	≥4 years	<4 years (before conception)	Since conception	*p*-value *
Duration of ART				
Before conception	1315 (50.4)	495 (24.3)	30 (8.0)	<0.001
12-40 weeks	873 (33.5)	921 (45.2)	119 (31.7)	
2-11 weeks	395 (15.2)	584 (28.7)	179 (47.7)	
<2 weeks	24 (0.9)	36 (1.8)	47 (12.5)	
Mode of delivery				
Elective CS	1188 (46.6)	1051 (50.7)	235 (55.6)	0.002
Emergency CS	643 (25.2)	503 (24.2)	91 (21.5)	
Vaginal	720 (28.2)	521 (25.1)	97 (22.9)	
Gestational age (weeks)¶¶				
≥ 37	2206 (86.5)	1810 (87.2)	367 (87.0)	0.789
<37	343 (13.5)	265 (12.8)	55 (13.0)	

† Numbers vary due to missing data. * *p*-value obtained using χ^2test. ¶ First reported value in pregnancy. ¶¶ Restricted to live and still births.
Col, column; ART, antiretroviral therapy; CS, Caesarean Section.

4.5 Conclusions

The number of pregnancies reported in the UK in women diagnosed with HIV increased dramatically between 1990 and 2006, although numbers have plateaued to approximately 1400 pregnancies a year since then. The number of reports in African women increased substantially over this time period with three quarters of all pregnancies reported annually to the NSHPC since 2002 being in African women. This is due to a combination of increasing prevalence of HIV in Sub-Saharan Africa, increasing migration from Africa to the UK (Owen 2009)[141] and the advent of routine antenatal HIV screening in the late 1990s (Townsend et al. 2006). The number of pregnancies reported in African women has stabilised since 2006, partly reflecting the plateauing of immigration to the UK (including from Commonwealth nations) in recent years (Rienzo et al. 2012).

Centres in London reported the largest number of pregnancies in HIV-positive women, the overwhelming majority being in African women. However, outside London the number of pregnancies reported to the NSHPC has also increased over time, again mainly in African women. The increasing numbers of pregnancies reported to the NSHPC in African women *across* the UK is likely to be due to a combination of the routine dispersal of asylum seekers away from the South East of England since the implementation of the 1999 Immigration and Asylum Act in 2000[142] (Stewart 2012) as well as widespread HIV antenatal screening being rolled out across the UK.

The greatest number of reported pregnancies in African women diagnosed with HIV was in women from Eastern Africa. This is unsurprising given that many Eastern African countries (such as Uganda, Tanzania, Kenya and Zimbabwe) are current or former members of the Commonwealth of Nations and have well established links with the UK. In the 1990s the majority of pregnancies in African women that were reported to the NSHPC were in Ugandans, probably a reflection of forced migration due to the Ugandan Civil War and the concentration of the early HIV epidemic in Eastern Africa. In recent years, Zimbabwean women predominate, reflecting the surge of Zimbabweans seeking political asylum in the UK in the late 1990s and early 2000s as a result of the

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[141] Also see data from the 2001 and 2011Census for England and Wales available at http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/sty-non-uk-born-population.html (accessed 23 September 2013).

[142] Since 2000 the UK Home Office policy has operated a compulsory dispersal policy where asylum seekers are housed on a no-choice basis in locations mainly situated outside of the South east of the UK and London in an effort to distribute housing, social and financial pressures amongst local authorities throughout the country.

political instability in Zimbabwe since the mid-1990s (Owen 2009). More broadly, there has been a diversification in terms of region of birth among African women reported to the NSHPC since the late 1990s. The number of pregnancies in women from Eastern Africa increased from 1990 to 2010, although the overall proportion declined. In the same time period the number of pregnancies in women from Western Africa (predominantly Nigeria) increased to a point where nearly one in four HIV-positive women reported as pregnant to the NSHPC were from western African. This echoes the diversification in African region of birth of the HIV seen in Black Africans in the general adult HIV-positive population in the UK between 2001 and 2010 (Meaghan Kall, Public Health England, personal communication, 25 June 2012). This reflects migration patterns to England and Wales in that there has been a greater increase in numbers of residents in England and Wales who were born in Western and Central Africa compared with those born in Southern and Eastern Africa[143]. In later years, with increasing sequential pregnancies, it may also reflect underlying differential fertility patterns among African women (French et al. 2011).

Between 1990 and 2010 the median duration of residence at conception among African women increased. This trend towards increasing duration of residence at the time of conception may be a result of increasingly stringent UK immigration policy since the late 1990s (Somerville 2007). It is also important to note that early in the study period there was little availability of ART. African women migrating to the UK in the early 1990s (who were likely to have acquired HIV prior to migration) would not have had access to effective treatment and therefore would have been less likely to survive to have a long interval between arrival in the UK and becoming pregnant.

Chapters Five, Seven and Eight of this thesis focus on pregnancies reported to the NSHPC between 2000 and 2010. Looking briefly at this group, we see that it was more common for African women to have been diagnosed with HIV during their reported pregnancy than it was for white British women. In particular, African women who had arrived in the UK after conception, as well as women from Southern and Western Africa, were more likely to have been diagnosed during pregnancy. As a result only a small proportion of these women were on ART at conception and hence they were more likely to have a detectable initial HIV viral load in pregnancy. Those who arrived in the

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[143] Data from 2001 England and Wales Census available from table UV08 at http://www.ons.gov.uk/ons/datasets-and-tables/index.html (accessed 23 September 2013) and data from 2011 England and Wales Census available from table QS213EW at http://www.nomisweb.co.uk/census/2011/qs213ew (accessed 23 September 2013).

UK after conception were also more likely to have had an elective caesarean section, probably reflecting shorter duration of ART and lack of virological suppression towards the end of pregnancy. In the following chapter I explore the use of ART among African women living with HIV in greater detail.

Key Points

- African women were the largest group of women reported to the NSHPC between 1900 and 2010, with London reporting the largest numbers of pregnant African women living with HIV.

- Eastern Africans (initially Ugandan and more recently Zimbabwean) were the largest group of African women reported to the NSHPC, however there have been recent increases in other groups, most notably Western Africans (mainly Nigerians). This echoes trends in the general adult HIV-positive population and mainly reflects trends in African migration to the UK since the early 1990s.

- Over time, African women have been resident in the UK for a longer period of time at the time of conception.

- Over the past ten years, an increasing number of pregnancies in African women has been reported outside of London.

- Demographic and clinical differences have been seen among African women, with Southern and Western African women more likely to be diagnosed with HIV during pregnancy, as were those who had arrived in the UK after conception.

- The findings in this chapter highlight the changing epidemiology of HIV and pregnancy *among* African women and suggest that there may be differences in terms of clinical outcomes within this broad ethnic group.

5

Using antiretroviral therapy in pregnancy

Summary

A central component in the management of HIV in pregnancy is the use of ART. In this mixed methods chapter I use data from the NSHPC to examine the relationship between maternal ethnicity, African region of birth and duration of residence in the UK, and the following key indicators: (i) not receiving ART during pregnancy (ii) detectable maternal HIV viral load at delivery and (iii) vertical transmission of HIV. I then present ethnographic data, based mainly on interviews with pregnant women and their healthcare providers, in order to explore women's experiences of taking, or not taking, ART during pregnancy. Through the dialogic movement between quantitative and qualitative findings, I aim to provide a multidimensional account of the processes that shape African women's use of ART during pregnancy.

5.1 Introduction

The overarching research question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? In Chapter One I outlined the changing epidemiology of HIV in the last three decades, with an increase in heterosexually acquired infection in the UK and a rise in the number of pregnancies in HIV-positive women in the UK. I also highlighted the paucity of literature on HIV and pregnancy that engages with outcomes other than those that directly affect the infant. Furthermore I discussed the lack of work to date that explores the impact of ethnicity, and the heterogeneity within ethnic groups, on pregnancy and motherhood in the context of HIV. This is a notable lacuna since African women represent over three quarters of HIV-positive women reported as pregnant in the UK each year and that there has been a diversification in African women's region of birth (as described in Chapter Four).

A central component in the management of HIV in pregnancy is the use of antiretroviral therapy (ART). The clinical indications for ART in pregnancy in the UK are relatively straightforward (Taylor et al. 2012). *All* women diagnosed with HIV are advised to take ART during pregnancy to prevent vertical transmission of the virus. Some women will have been on treatment for some time for their own health and will therefore continue on the same medication regime throughout their pregnancy. Others will start treatment during pregnancy for their own health, either because they are at risk of an opportunistic infection or their CD4 count has fallen below the threshold for starting treatment, as well as for the prevention of vertical transmission. A third group of women will not require treatment for their own health and the only indication for ART will be for the prevention of vertical transmission. Regardless of the situation, most women will be advised to be on treatment by fourteen to twenty-four weeks of pregnancy at the latest (Ibid.). Therefore, within this group of women taking ART there are important differences according to women's experience of taking ART and the clinical reasons underlying their treatment. Already we can begin to make out a complexity that belies the apparent straightforwardness of clinical guidelines.

Furthermore, there are important dichotomies that lie at the heart of treating HIV during pregnancy. Women living with HIV are advised to take medication to safeguard the health of their child during pregnancy, the very time in which most women are advised to exercise caution when ingesting any substance whether that be food or medication. This leads us to ask: what does it mean to take ART during pregnancy, and is African women's use of ART shaped by ethnicity, African region of birth and duration of residence in the UK?

5.2 Epidemiological data on uptake of antiretroviral therapy

Uptake and adherence to ART is the cornerstone of treatment of HIV in pregnancy in order to reduce maternal HIV viral load in the blood and genital secretions, therefore minimising the risk of vertical transmission. Furthermore, if a woman has a compromised immune system ART is the key to restoring immune-function and safeguarding long-term health. In this section I explore the association between uptake of ART and: (i) maternal ethnicity, (ii) maternal African region of birth, and (iii) maternal duration of residence in the UK at conception (for African women). The analysis of uptake of ART excluded ectopic pregnancies and pregnancies resulting in termination or miscarriage, as it would be unlikely that there would have been an indication or opportunity to take ART. ART referred to any antiretroviral medication whether monotherapy, dual therapy or HAART. Potential confounding variables included maternal age, history of injecting drug use, reporting region, timing of HIV diagnosis and gestational age. Robust standard errors were used to account for possible clustering of maternal-level effects in women who had more than one pregnancy. Uptake of treatment was defined as whether a woman was reported to have received treatment with ART at any point during her pregnancy and was categorised as "yes" or "no"[144].

5.2.1 Results

There were 9214 eligible pregnancies with a delivery date or expected delivery date between January 2000 and December 2010. This analysis is based on 8997/9214 (97.6%) pregnancies with data available on uptake of ART in 7228 women[145]. Demographic and clinical characteristics of the study population are presented in table 5.1. Nearly 90% (88.8%) of pregnancies were in women who were of African ethnicity. Overall, in 2.6% (233/8997; 95% confidence interval [CI]: 2.3%, 2.9%) of pregnancies women were not reported to have received ART; this did not differ significantly between white British and African women ($p > 0.5$, table 5.1).

In almost 30% (67/233) of pregnancies where women were not reported to have received ART, this was because she was documented as having declined treatment. Of those who didn't receive ART during pregnancy, a greater proportion of African women declined treatment (64/205; 31.2%) compared with white British women (3/28; 10.7%; $p < 0.05$). Women born in Western Africa (22/62; 35.5%) and Middle Africa (14/26; 50.0%) were more likely to decline treatment than those from Eastern Africa (27/100; 27.0) and Southern Africa (1/15; 6.7%; $p < 0.05$). Small numbers precluded any further meaningful statistical analysis.

The percentage of pregnancies where the mother had not received ART during pregnancy fell from 11.4% in 2000 to 1.1% in 2010 (χ^2_{trend} test $p < 0.001$, figure 5.1). Over 90% (7839/8672) of women who took ART during pregnancy took HAART with 731 (8.4%) taking monotherapy and 102 (1.2%) taking dual therapy.

On univariable analysis there was an association between not receiving ART in pregnancy and younger maternal age at delivery, the route of maternal HIV acquisition being injecting drug use (IDU), HIV diagnosis during the reported pregnancy, higher

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[144] This excluded pregnancies in which women received *only* intrapartum ART.

[145] Some women had more than once pregnancy reported to the NSHPC.

initial HIV viral load in pregnancy, preterm delivery and pregnancy earlier in the study period (all $p<0.05$, table 5.1). There was no association between uptake of ART and either earliest CD4 count or reporting area ($p>0.1$).

Just under 3% (28/1007; 2.8%) of women of white British ethnicity did not receive ART during pregnancy; similar to the percentage of African women (205/7990, 2.6%; odds ratio (OR) 0.92; 95% CI: 0.62, 1.37; $p>0.1$, table 5.2). After adjusting for year, history of IDU, timing of HIV diagnosis and gestation at delivery, the odds of not receiving ART in African women remained similar to that in white British women (adjusted odds ratio (AOR 0.84); 95% CI: 0.53, 1.34; $p>0.1$, table 5.2).

Restricting the analysis to African women, 2.1% (100/4779) of Eastern African women did not receive ART during pregnancy. A greater proportion of Western African (62/1748; 3.6%) and Middle African (28/799; 3.5%) women did not receive ART during pregnancy (both $p<0.05$, table 5.3). After adjusting for year, timing of diagnosis and gestation at delivery, Middle African women's odds of not receiving ART were similar to those of women from Eastern Africa (AOR 1.47; 95% CI: 0.82, 2.63; $p>0.1$; table 5.3). However, after adjusting for the same factors, the odds of not receiving ART during pregnancy remained increased in Western African women compared with those from Eastern Africa (AOR 1.77; 95% CI: 1.19, 2.63; $p<0.01$, table 5.3). There are differences in median duration of residence in the UK at conception according to African region of birth[146]. I explored the effects of duration of residence in the UK on the association between Western African ethnicity and not taking ART by including it in the multivariable model. The odds of not taking ART in pregnancy remained increased for Western African women although this was now of borderline significance, possibly as a result of smaller numbers (AOR 1.54; 95% CI: 0.94, 2.52; $p=0.088$).

Among African women, a greater proportion of those who had arrived in the UK after conception had not received ART during pregnancy (7.4%; 33/444) than those who had been in the UK for less than 4 years (2.2%; 46/2142) and those who had been in the UK for ≥ 4 years (2.0%; 53/2653). In fact, on multivariable analysis adjusting for maternal age, year, timing of HIV diagnosis and gestation at delivery, African women who had arrived in the UK after conception had over twice the odds of not receiving ART during pregnancy compared with those who had been in the country for ≥ 4 years (AOR 2.31; 95% CI: 1.31, 4.08; $p<0.05$, table 5.4).

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[146] See Chapter Four (table 4.4: 102).

Table 5.1: Characteristics of women with pregnancies reported to the NSHPC by receipt of antiretroviral therapy, 2000-2010

	ART, n (row %) n=8764	No ART, n (row %) n=233	*p*-value*
Ethnicity, n=8997			
White British	979 (97.2)	28 (2.8)	0.686
African	7785 (97.4)	205 (2.6)	
Maternal age at delivery, n=8613			
<25 years	1147 (96.5)	42 (3.5)	0.002
25-34 years	5199 (97.6)	128 (2.4)	
≥35 years	2063 (98.4)	34 (1.6)	
Year of EDD/delivery, n=997			
2000-2003	1818 (94.4)	108 (5.6)	<0.001
2004-2006	2737 (97.4)	73 (2.6)	
2007-2010	4209 (98.8)	52 (1.2)	
IDU, n=8997			
No	8686 (97.5)	226 (2.5)	0.001
Yes	78 (91.8)	7 (8.2)	
Timing of HIV diagnosis, n=8975			
Before conception	5129 (98.5)	77 (1.5)	<0.001
During pregnancy	3613 (95.9)	156 (4.1)	
Reporting areas, n=8611			
London	4053 (97.2)	115 (2.8)	0.081
England (not London)	3916 (98.0)	80 (2.0)	
Scotland, Wales, NI	436 (97.5)	11 (2.5)	
Timing of antenatal booking, n=2554			
1st trimester	1243 (99.1)	11 (0.9)	0.226
2nd/3rd trimester	1282 (98.6)	18 (1.4)	
Earliest HIV viral load¶, copies/ml, n=7482			
≤50	2692 (99.3)	19 (0.7)	<0.001
51-10000	2844 (98.1)	55 (1.9)	
>10,000	1844 (98.5)	28 (1.5)	
Earliest CD4 count¶, cells/µl, n=8074			
≥350	4539 (98.0)	92 (2.0)	0.272
200-249	2294 (98.5)	36 (1.6)	
<200	1097 (98.6)	16 (1.4)	
Gestation at delivery, n=8358			
≥37 weeks	7176 (97.9)	158 (2.2)	0.020
<37 weeks	1165 (96.8)	39 (3.2)	

*Obtained using χ^2 test. ¶ First reported value in pregnancy. ART, antiretroviral therapy; EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; NI, Northern Ireland.

Figure 5.1: Trends over time in women not receiving ART during pregnancy, 2000-2010

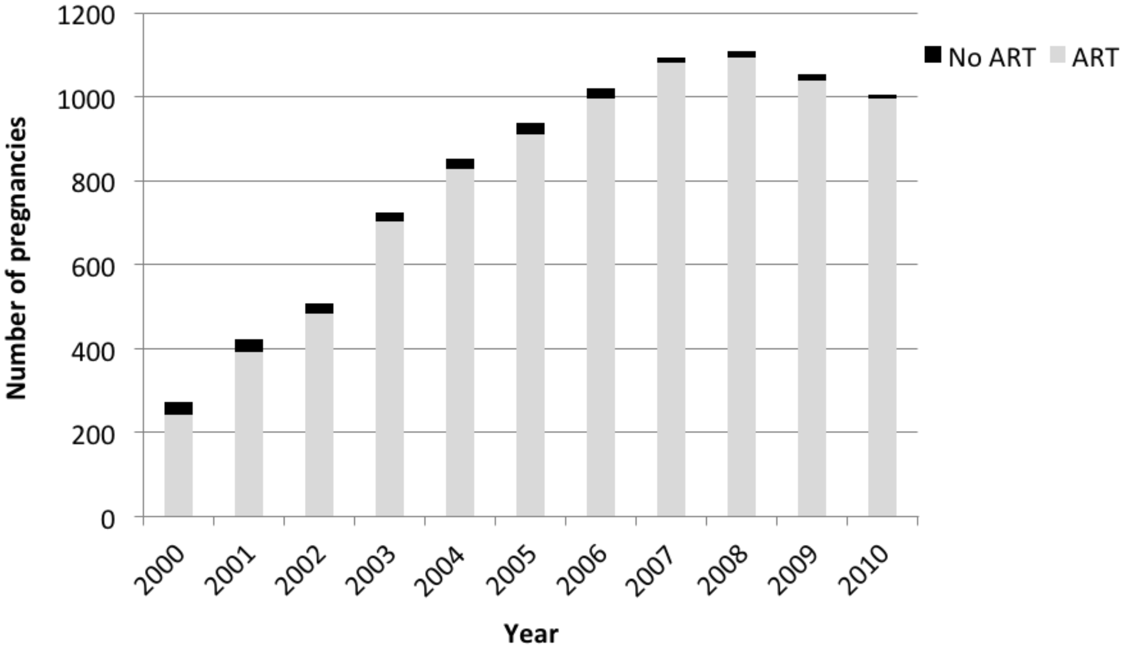

Table 5.2: Univariable and multivariable analysis of the association between ethnicity and not receiving antiretroviral therapy during pregnancy

		Univariable analysis		Multivariable analysis, n= 8518	
	No ART/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Ethnicity					
White British	28/1007 (2.8)	1.00		1.00	
African	205/7990 (2.6)	0.92 (0.62,1.37)	0.686	0.84 (0.53,1.34)	0.465
Maternal age at delivery					
<25 years	42/1189 (3.5)	1.00	0.003		
25-34 years	128/5327 (2.4)	0.67 (0.47,0.96)			
≥35 years	34/2097 (1.6)	0.45 (0.28,0.71)			
Year of EDD/delivery					
2000-2003	108/1926 (5.6)	1.00	<0.001	1.00	
2004-2006	73/2810 (2.6)	0.45 (0.33,0.61)		0.37 (0.26,0.53)	<0.001
2007-2010	52/4261 (1.2)	0.15 (0.15,0.29)		0.27 (0.18,0.40)	<0.001
IDU					
No	226/8912 (2.5)	1.00	0.008	1.00	
Yes	7/85 (8.2)	3.45 (1.57,7.56)		3.06 (1.04,8.97)	0.042
Reporting areas					
London	115/4168 (2.8)	1.00	0.080		
England (not London)	80/3996 (2.0)	0.72 (0.54,0.96)			
Scotland, Wales, NI	11/447 (2.5)	0.89 (0.48,1.66)			
Timing of HIV diagnosis					
Before conception	77/5206 (1.5)	1.00	<0.001	1.00	
During pregnancy	156/3769 (4.1)	2.88 (2.18,3.79)		2.46 (1.74,3.47)	<0.001
Timing of antenatal booking					
1st trimester	11/1254 (0.9)	1.00	0.224		
2nd/3rd trimester	18/1300 (1.4)	1.59 (0.75,3.37)			

Table 5.2 continued

		Univariable analysis		Multivariable analysis	
	No ART/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Gestation at delivery					
≥37 weeks	158/7334 (2.2)	1.00	0.027	1.00	
<37 weeks	39/1204 (3.2)	1.52 (1.07,2.17)		1.50 (1.04,2.16)	0.032

OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; NI, Northern Ireland.

Table 5.3: Univariable and multivariable analysis of the association between African region of birth and not receiving antiretroviral therapy during pregnancy (restricted to African women)

		Univariable analysis		Multivariable analysis, n=7548	
	No ART/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
African region of birth					
Eastern Africa	100/4779 (2.1)	1.00		1.00	
Southern Africa	15/644 (2.3)	1.12 (0.65,1.94)	0.684	0.91 (0.45,1.82)	0.784
Western Africa	62/1748 (3.6)	1.73 (1.25,2.83)	0.001	1.77 (1.19,2.63)	0.005
Middle Africa	28/799 (3.5)	1.71 (1.11,2.61)	0.014	1.47 (0.82,2.63)	0.200
Maternal age at delivery					
<25 years	31/894 (3.5)	1.00	0.008		
25-34 years	116/4841 (2.4)	0.68 (0.46,1.02)			
≥35 years	30/1985 (1.6)	0.45 (0.27,0.74)			
Year of EDD/delivery					
2000-2003	92/1680 (5.5)	1.00	<0.001	1.00	
2004-2006	67/2515 (2.7)	0.47 (0.34,0.65)		0.38 (0.26,0.56)	<0.001
2007-2010	46/3795 (1.2)	0.21 (0.15,0.30)		0.26 (0.17,0.41)	<0.001
IDU					
No	205/7987 (2.6)				
Yes	0/3 (0)				
Reporting areas					
London	105/3959 (2.7)	1.00	0.184		
England (not London)	69/3419 (2.0)	0.76 (0.56,1.03)			
Scotland, Wales, NI	5/252 (2.0)	0.74 (0.30,1.84)			
Timing of HIV diagnosis					
Before conception	63/4559 (1.4)	1.00	<0.001	1.00	
During pregnancy	142/3409 (4.2)	3.10 (2.30,4.19)		2.55 (1.73,3.76)	<0.001

Table 5.3 continued

		Univariable analysis		Multivariable analysis	
	No ART/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Timing of antenatal booking					
1st trimester	10/1088 (0.9)	1.00	0.440		
2nd/3rd trimester	15/1196 (1.3)	1.37 (0.61,3.06)			
Gestation at delivery					
≥37 weeks	137/6532 (2.1)	1.00	0.024	1.00	
<37 weeks	34/1036 (3.3)	1.58 (1.08,2.32)		1.60 (1.09,2.35)	0.016

OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; NI, Northern Ireland.

Table 5.4: Univariable and multivariable analysis of the association between maternal duration of residence in the UK at conception and not receiving antiretroviral therapy during pregnancy (restricted to African women)

		Univariable analysis		Multivariable analysis, n=5018	
	No ART/N (%)	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Duration of residence in UK					
≥ 4 years	53/2653 (2.0)	1.00		1.00	
< 4 years (before conception)	46/2142 (2.2)	1.08 (0.72,1.60)	0.717	0.70 (0.41,1.20)	0.193
Since conception	33/444 (7.4)	3.94 (2.52,6.16)	<0.001	2.31 (1.31,4.08)	0.004
Maternal age at delivery					
<25 years	20/595 (3.4)	1.00	0.009	1.00	
25-34 years	81/3190 (2.5)	0.75 (0.46,1.23)		0.90 (0.52,1.56)	0.706
≥35 years	17/1261 (1.4)	0.39 (0.20,0.76)		0.54 (0.26,1.13)	0.101
Year of EDD/delivery					
2000-2003	60/1114 (5.4)	1.00	<0.001	1.00	
2004-2006	44/1682 (2.6)	0.47 (0.32,0.70)		0.45 (1.31,4.08)	0.001
2007-2010	28/2443 (1.2)	0.20 (0.13,0.32)		0.23 (0.28,0.71)	<0.001
IDU					
No	132/5238 (2.5)				
Yes	0/1 (0)				
Reporting areas					
London	74/2880 (2.6)	1.00	0.453		
England (not London)	41/2006 (2.0)	0.79 (0.54,1.16)			
Scotland, Wales, NI	3/157 (1.9)	0.74 (0.23,2.37)			
Timing of HIV diagnosis					
Before conception	43/3044 (1.4)	1.00	<0.001	1.00	
During pregnancy	89/2190 (4.1)	2.96 (2.05,4.27)		2.46 (1.74,3.47)	<0.001

Table 5.4 continued

		Univariable analysis		Multivariable analysis	
	No ART/N (%)	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Timing of antenatal booking					
1st trimester	9/699 (1.3)	1.00	0.500		
2nd/3rd trimester	7/761 (0.9)	0.71 (0.26,1.92)			
Gestation at delivery					
≥37 weeks	90/4358 (2.1)	1.00	0.010	1.00	
<37 weeks	25/660 (3.8)	1.87 (1.19,2.93)		1.86 (1.19,2.90)	0.007

OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; NI, Northern Ireland.

5.3 Epidemiological data on detectable maternal HIV viral load at delivery

Lack of maternal virological suppression at delivery is the main mechanism for vertical transmission and can be due to either sub-optimal response (as a result of pharmacokinetics of ART during pregnancy, interactions with other medication or maternal drug resistance) or poor adherence[147] to medication. In this section I explore the association between detectable maternal HIV viral load at delivery and: (i) maternal ethnicity, (ii) maternal African region of birth, and (iii) maternal duration of residence in the UK at conception (for African women).

Analysis of viral load at delivery was restricted to live singleton births in women who received HAART during pregnancy. Stillbirths were excluded due to the possibility of maternal co-infections, such as syphilis, that may increase HIV viral load. Pregnancies in women taking mono/dual antiretroviral therapy were excluded, as these regimes would not be expected to result in virological suppression. HAART was defined as a regimen of three or more antiretroviral drugs. Type of HAART was categorised as: nucleoside reverse transcriptase inhibitor (NRTI) only, non-nucleoside reverse transcriptase inhibitor (NNRTI)-based, protease inhibitor (PI)-based, and HAART including both NNRTIs and PIs. Robust standard errors were used to account for possible clustering of maternal-level effects in women who had more than one pregnancy.

Viral load at delivery was defined as the closest reported maternal HIV viral load to delivery measured between twenty-eight days before and seven days after delivery. Delivery viral load was categorised as undetectable or detectable; ‘undetectable’ was defined as ≤50 copies/ml.

Maternal age, history of injecting drug use, first viral load in pregnancy, first CD4 count in pregnancy and HAART regime were considered as confounders in analyses. Duration of HAART was considered as a potential confounder in the analyses of viral load at delivery and both ethnicity and African region of origin. Duration of HAART was not included in the analysis of viral load at delivery and maternal duration of

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[147] I use the term ‘adherence’ throughout this thesis rather than ‘compliance’. Adherence in this context is widely understood to mean a person’s ability to take ART as prescribed. It has much more common usage in the field of HIV medicine than compliance and implies a degree of agency and choice in taking medication (Mykhalovskiy, et al. 2004).

residence in the UK at conception as it was thought to be on the causal pathway[148].

Due to the high proportion of missing viral load data in pregnancies (3189/7290, 43.7%), an imputed variable was used. If delivery viral load was missing but the last reported viral load during pregnancy (at any time point) was undetectable, then delivery viral load was imputed as undetectable. This was based on an assumption that women on HAART in pregnancy who achieved virological suppression would remain undetectable until delivery[149]. To ensure validity, a sensitivity analysis was conducted by running all multivariable analyses using both the imputed and non-imputed[150] delivery viral load data.

5.3.1 Results

There were 7290 eligible pregnancies in women on HAART during the study period. This analysis is based on 6005/7290 (82.4%) pregnancies in 4991 women with available data on HIV viral load at delivery based on the imputed dataset. Again, the overwhelming majority of pregnancies were in African women (5362/6005; 89.3%). Other demographic and clinical characteristics of the study population are presented in table 5.5.

Using the non-imputed delivery viral load variable, HIV viral load at delivery was detectable in 28.8 % of pregnancies (1181/4101). A further 1904 values were imputed by assuming that viral load at delivery was undetectable if the last viral load in pregnancy (regardless of when this was taken in pregnancy) was undetectable. Using this imputed value, HIV viral load was detectable in almost 20% of pregnancies (1181/6005; 95% CI: 18.7%, 20.7%). This proportion fell from 29.2% in 2000 to 14.3% in 2010 (χ^2_{trend} test $p<0.001$, figure 5.2).

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[148] Its inclusion would introduce the possibility of over-adjustment (Schisterman, et al. 2009).

[149] A recent US study found that nearly 90% of women who were virologically suppressed on HAART earlier in pregnancy maintained virological suppression until delivery suggesting that this assumption was reasonable (Katz, et al. 2010).

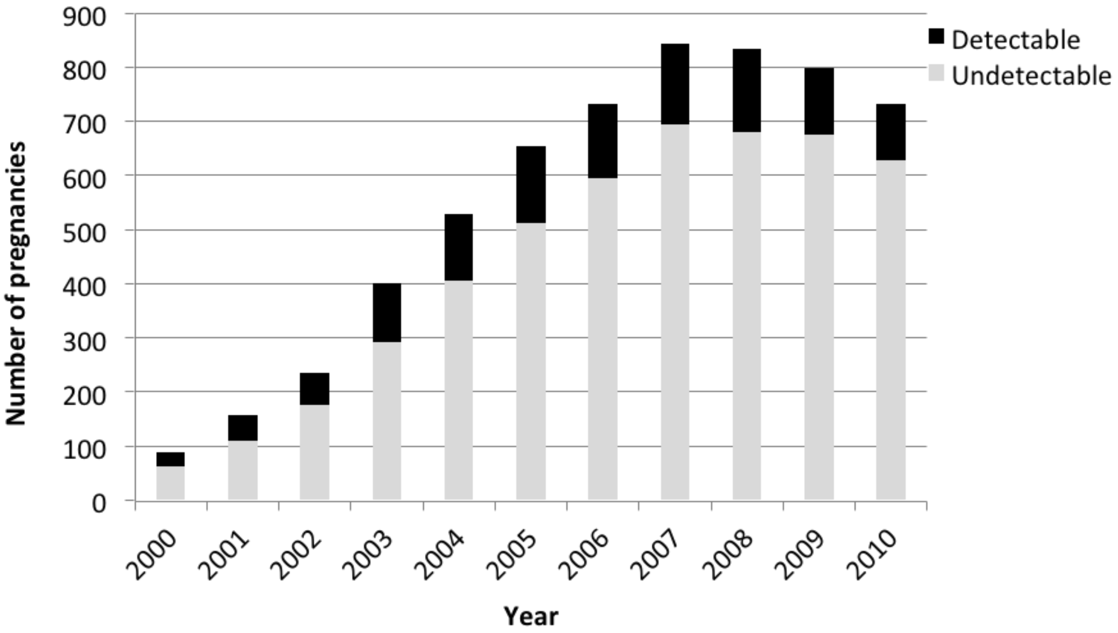
[150] Excluding the 3189 pregnancies where delivery viral load was missing.

Table 5.5: Characteristics of women on HAART with pregnancies reported to the NSHPC by HIV viral load at delivery, 2000-2010 (based on imputed dataset)

	Undetectable VL, n (row %) n=4824	Detectable VL, n (row %) n=1181	*p*-value*
Ethnicity, n=6005			
White British	532 (82.7)	111 (17.3)	0.105
African	4292 (80.0)	1070 (20.0)	
Maternal age at delivery, n=6005			
<25 years	515 (71.7)	203 (28.3)	<0.001
25-34 years	2958 (79.9)	743 (20.1)	
≥35 years	1351 (85.2)	235 (14.8)	
Year of EDD/delivery, n=6005			
2000-2003	640 (72.4)	244 (27.6)	<0.001
2004-2006	1510 (78.9)	404 (21.1)	
2007-2010	2674 (83.4)	533 (16.6)	
IDU, n=6005			
No	4793 (80.4)	1171 (19.6)	0.445
Yes	31 (75.6)	10 (24.4)	
Earliest HIV VL¶, copies/ml, n=5404			
≤50	2195 (95.9)	95 (4.2)	<0.001
51-10000	1467 (81.3)	338 (18.7)	
>10,000	800 (61.1)	509 (38.9)	
Earliest CD4 count¶, cells/µl, n=5875			
≥350	2773 (84.4)	513 (15.6)	<0.001
200-249	1397 (79.4)	362 (20.6)	
<200	565 (68.1)	265 (19.4)	
Type of HAART, n= 6005			
NRTI only	83 (89.3)	10 (10.8)	<0.001
NNRTI-based	1766 (85.7)	296 (14.4)	
PI-based	2682 (77.6)	776 (22.4)	
NNRTI/PI based	293 (74.7)	99 (25.3)	
Duration of HAART, n=5923			
On ART at conception	2045 (92.4)	169 (7.6)	<0.001
12-40 weeks	2080 (82.8)	431 (17.2)	
2-11 weeks	629 (58.2)	452 (41.8)	
<2 weeks	13 (11.1)	104 (88.9)	

* Obtained using χ^2 test. ¶ First reported value in pregnancy. VL, viral load; EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; HAART, highly active antiretroviral therapy; NRTI, nucleoside reverse transcriptase inhibitor; NNRTI, non-nucleoside reverse transcriptase inhibitor; PI, protease inhibitor.

Figure 5.2: Trends over time in HIV viral load at delivery in women on HAART during pregnancy, 2000-2010



In univariable analysis there was an association between detectable viral load at delivery and younger maternal age at delivery, higher earliest antenatal viral load, lower earliest antenatal CD4 count, HAART regime and shorter duration of ART (all $p<0.001$, table 5.5).

Nearly 20% (1070/5362) of African women had a detectable HIV viral load at delivery compared with 17.3% of white British women (111/643; OR 1.19; 95% CI: 0.96, 1.48; $p>0.05$, table 5.6). After adjusting for year, earliest antenatal viral load, earliest antenatal CD4 count, HAART regime and duration of ART, there was still no evidence of a difference between African women and white British women (AOR 1.08; 95% CI: 0.82, 1.41; $p>0.1$, table 5.6). A similar odds ratio was obtained when the multivariable analysis was repeated using the non-imputed delivery viral load variable (AOR 1.03; 95% CI: 0.77, 1.37; $p>0.1$).

Restricting the analysis to African women, a significantly higher proportion of Southern African women (22.7%; 96/423) and Western African women (23.0%; 270/1172) had a detectable delivery viral load compared with women from Eastern Africa (18.5%; $p<0.05$, table 5.7). After adjusting for year, earliest viral load, earliest CD4 count, HAART regime and duration of ART, there was no evidence of an association between

Southern or Western African region of birth and detectable viral load at delivery (both $p>0.1$; table 5.7). Similar odds ratios were obtained when repeating the multivariable analysis using the non-imputed delivery viral load variable for both Southern African women (AOR 1.03; 95% CI: 0.74, 1.44; $p>0.1$) and Western African women (AOR 1.05; 95% CI: 0.77, 1.46).

Among African women, a much higher percentage of those who had arrived in the UK after conception had a detectable HIV viral load at delivery (43.0%; 110/256) than those who had been in the UK for less than 4 years (19.5%; 283/1450) and those who had been in the UK for ≥ 4 years (15.9%; 313/1969). This group had four times the odds of having a detectable viral load at delivery compared with those who had been in the country for ≥ 4 years (OR 3.99; 95% CI: 3.03, 5.25; $p<0.001$, table 5.8). After adjusting for year, earliest viral load, earliest CD4 count, HAART regime and duration of HAART, the odds of having a detectable viral load at delivery were still over twice as high for women arriving in the UK after conception than those who had been in the UK for ≥ 4 years (AOR 2.29; 95% CI: 1.61, 3.26: $p<0.001$, table 5.8).

On repeating the multivariable analysis using the non-imputed viral load variable, there was little difference in the odds ratio (AOR 2.03: 95% CI: 1.40, 2.95; $p<0.001$). I hypothesised that the effects of shorter duration of residence in the UK on viral load at delivery were mainly mediated by duration of ART *i.e.* if a woman arrived after conception she would have been likely to have less opportunity to start ART in a timely fashion, a critical predictor of viral load at delivery. I therefore repeated the analysis adjusting for duration of ART, to investigate whether this was an important mediating factor. I found that although the adjusted odds ratio was attenuated, there remained increased odds of having a detectable viral load in the group of women arriving in the country after conception (AOR 1.49: 95% CI: 1.02, 2.18; $p<0.05$).

Table 5.6: Univariable and multivariable analysis of the association between ethnicity and detectable HIV viral load at delivery (based on imputed dataset)

		Univariable analysis		Multivariable analysis, n=5280	
	Detectable VL/N (%)	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Ethnicity					
White British	111/643 (17.3)	1.00		1.00	
African	1070/5362 (20.0)	1.19 (0.96,1.48)	0.100	1.08 (0.82,1.41)	0.583
Maternal age at delivery					
<25 years	203/718 (28.3)	1.00	<0.001		
25-34 years	743/3701 (20.1)	0.64 (0.53,0.76)			
≥35 years	235/1586 (14.8)	0.44 (0.36,0.55)			
Year of EDD/delivery					
2000-2003	244/884 (27.6)	1.00	<0.001	1.00	
2004-2006	404/1914 (21.1)	0.70 (0.58,0.84)		0.72 (0.54,0.95)	0.004
2007-2010	533/3207 (16.6)	0.52 (0.44,0.62)		0.69 (0.53,0.89)	0.005
IDU					
No	1171/5964 (19.6)	1.00	0.458		
Yes	10/41 (24.4)	1.32 (0.65,2.70)			
Earliest viral load[¶], copies/ml					
≤50	95/2290 (4.2)	1.00	<0.001	1.00	
51-10000	338/1805 (18.7)	5.32 (4.20,6.75)		4.76 (3.44,6.59)	<0.001
>10,000	509/1309 (38.9)	14.70 (11.64,18.57)		14.32 (10.18,20.14)	<0.001
Earliest CD4 count[¶], cells/µl					
≥350	513/3286 (15.6)	1.00	<0.001	1.00	
200-249	362/1759 (20.6)	1.40 (1.21,1.63)		1.11 (0.92,1.34)	0.266
<200	265/830 (31.9)	2.54 (2.13,3.01)		1.88 (1.48,2.37)	<0.001

Table 5.6 continued

		Univariable analysis		Multivariable analysis	
	Detectable VL/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Type of HAART					
NRTI only	10/93 (10.8)	1.00	<0.001	1.00	
NNRTI-based	296/2062 (14.4)	1.39 (0.71,2.71)		1.14 (0.42,3.04)	0.800
PI-based	776/3458 (22.4)	2.40 (1.24,4.65)		2.19 (0.83,5.78)	0.113
NNRTI/PI based	99/392 (25.3)	2.80 (1.40,5.62)		2.15 (0.92,1.34)	0.140
Duration of HAART					
On HAART at conception	169/2214 (7.6)	1.00	<0.001	1.00	
12-40 weeks	431/2511 (17.2)	2.51 (2.08,3.03)		0.53 (0.40,0.72)	<0.001
2-11 weeks	452/1081 (41.8)	8.70 (7.13,10.60)		2.15 (1.58,2.93)	<0.001
<2 weeks	104/117 (88.9)	96.80 (53.3,175.95)		15.37 (7.26,32.52)	<0.001

¶ First reported value in pregnancy. VL, viral load; OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; HAART, highly active antiretroviral therapy; NRTI, nucleoside reverse transcriptase inhibitor; NNRTI, non-nucleoside reverse transcriptase inhibitor; PI, protease inhibitor.

Table 5.7: Univariable and multivariable analysis of the association between African region of birth and detectable HIV viral load at delivery (restricted to African women, based on imputed dataset)

		Univariable analysis		Multivariable analysis, n=4712	
	Detectable VL/N (%)	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
African region of birth					
Eastern Africa	600/3248 (18.5)	1.00		1.00	
Southern Africa	96/423 (22.7)	1.30 (1.01,1.65)	0.038	1.08 (0.78,1.48)	0.646
Western Africa	270/1172 (23.0)	1.32 (1.12,1.55)	0.001	1.09 (0.88,1.35)	0.426
Middle Africa	104/519 (20.0)	1.11 (0.88,1.40)	0.396	1.17 (0.87,1.58)	0.309
Maternal age at delivery					
<25 years	159/538 (29.6)	1.00	<0.001		
25-34 years	691/3384 (20.4)	0.61 (0.50,0.75)			
≥35 years	220/1440 (15.3)	0.43 (0.34,0.54)			
Year of EDD/delivery					
2000-2003	221/780 (28.3)	1.00	<0.001	1.00	
2004-2006	371/1711 (21.7)	0.70 (0.58,0.85)		0.67 (0.51,0.89)	0.005
2007-2010	478/2871 (16.7)	0.51 (0.42,0.61)		0.66 (0.51,0.87)	0.003
IDU					
No	1070/5361 (20.0)				
Yes	0/1 (0)				
Earliest viral load[¶], copies/ml					
≤50	91/2034 (4.5)	1.00	<0.001	1.00	
51-10000	305/1618 (18.9)	4.96 (3.88,6.33)		4.51 (3.22,6.33)	<0.001
>10,000	453/1161 (39.0)	13.66 (10.73,17.39)		13.54 (9.49,19.33)	<0.001
Earliest CD4 count[¶], cells/µl					
≥350	448/2860 (15.7)	1.00	<0.001	1.00	
200-249	335/1615 (20.7)	1.41 (1.20,1.65)		1.11 (0.91,1.35)	0.318
<200	255/782 (32.6)	2.61 (2.18,3.12)		1.98 (1.55,2.52)	<0.001

Table 5.7 continued

		Univariable analysis		Multivariable analysis	
	Detectable VL/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Type of HAART					
NRTI only	10/76 (13.2)	1.00	<0.001	1.00	
NNRTI-based	270/1863 (14.5)	1.12 (0.57,2.20)		0.98 (0.35,2.72)	0.972
PI-based	698/3064 (22.8)	1.95 (1.00,3.81)		1.93 (0.71,5.29)	0.199
NNRTI/PI based	92/359 (25.6)	2.27 (1.12,4.61)		1.83 (0.64,5.25)	0.261
Duration of HAART					
On HAART at conception	162/1991 (8.1)	1.00	<0.001	1.00	
12-40 weeks	383/2218 (17.3)	2.36 (1.94,2.86)		0.50 (0.37,0.68)	<0.001
2-11 weeks	404/974 (41.5)	8.00 (6.52,9.82)		1.96 (1.43,2.70)	<0.001
<2 weeks	97/107 (90.7)	109.51 (56.01,214.12)		17.45 (7.85,38.79)	<0.001

¶ First reported value in pregnancy. VL, viral load; OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; HAART, highly active antiretroviral therapy; NRTI, nucleoside reverse transcriptase inhibitor; NNRTI, non-nucleoside reverse transcriptase inhibitor; PI, protease inhibitor.

Table 5.8: Univariable and multivariable analysis of the association between maternal duration of residence in the UK at conception and detectable HIV viral load at delivery (restricted to African women, based on imputed dataset)

		Univariable analysis		Multivariable analysis, n=3319	
	Detectable VL/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Duration of residence in UK					
≥ 4 years	313/1969 (15.9)	1.00		1.00	
< 4 years (before conception)	283/1450 (19.5)	1.28 (1.07,1.53)	0.006	0.83 (0.67,1.03)	0.094
Since conception	110/256 (43.0)	3.99 (3.03,5.25)	<0.001	2.29 (1.61,3.26)	<0.001
Maternal age at delivery					
<25 years	100/384 (26.0)	1.00	<0.001		
25-34 years	457/2308 (19.8)	0.70 (0.55,0.90)			
≥35 years	149/980 (15.2)	0.51 (0.38,0.68)			
Year of EDD/delivery					
2000-2003	152/540 (28.2)	1.00	<0.001	1.00	
2004-2006	252/1204 (20.9)	0.68 (0.54,0.85)		0.59 (0.43,0.82)	0.002
2007-2010	302/1929 (15.7)	0.47 (0.38,0.59)		0.45 (0.32,0.62)	<0.001
IDU					
No	706/3672 (19.2)				
Yes	0/0 (0)				
Earliest viral load[¶], copies/ml					
≤50	58/1405 (4.1)	1.00	<0.001	1.00	
51-10000	213/1138 (18.7)	5.35 (3.95,7.23)		4.47 (3.25,6.15)	<0.001
>10,000	306/810 (37.8)	14.10 (10.46,19.01)		11.48 (8.32,15.85)	<0.001
Earliest CD4 count[¶], cells/µl					
≥350	307/1975 (15.5)	1.00	<0.001	1.00	
200-249	220/1113 (19.8)	1.34 (1.11,1.62)		0.99 (0.79,1.25)	0.959
<200	168/535 (31.4)	2.49 (2.00,3.10)		1.47 (1.11,1.96)	0.007

Table 5.8 continued

		Univariable analysis		Multivariable analysis	
	Detectable VL/N (%)	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Type of HAART					
NRTI only	7/56 (12.5)	1.00	<0.001	1.00	
NNRTI-based	190/1326 (14.3)	1.17 (0.52,2.62)		0.90 (0.34,2.38)	0.831
PI-based	444/2029 (21.9)	1.96 (0.88,4.36)		1.58 (0.61,4.08)	0.346
NNRTI/PI based	65/261 (24.9)	2.32 (1.00,5.38)		1.76 (0.64,4.82)	0.275

¶ First reported value in pregnancy. VL, viral load; OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; HAART, highly active antiretroviral therapy; NRTI, nucleoside reverse transcriptase inhibitor; NNRTI, non-nucleoside reverse transcriptase inhibitor; PI, protease inhibitor.

5.4 Epidemiological data on vertical transmission of HIV

As discussed in Chapter Two, annual rates of vertical transmission in the UK have been low at approximately 1% since 2000 as a result of the introduction of routine antenatal HIV testing, the use of ART in pregnancy, appropriate management of delivery and the avoidance of breastfeeding. In this section I explore the association between vertical transmission and: (i) maternal ethnicity, (ii) maternal African region of birth, and (iii) maternal duration of residence in the UK at conception (for African women). The analysis of vertical transmission was restricted to singleton live births. No women delivered more than one HIV-infected child between 2000 and 2010 and therefore robust standard errors were not required for this analysis.

Infant infection status was classified as uninfected or infected on the basis of reported polymerase chain reaction (PCR) or HIV antibody results[151].

Potential confounders considered in the following analysis included maternal age, history of injecting drug use, duration of ART, CD4 count at delivery, gestational age at delivery, mode of delivery and infant sex. Viral load at delivery was not included in the analysis despite being a recognised risk factor for vertical transmission as it was likely to be on the causal pathway. I hypothesised that adherence was the main mediating factor between all exposure variables and vertical transmission and that viral load at delivery would mediate the relationship between adherence (which is unmeasured in this dataset) and vertical transmission.

5.4.1 Results

There were 8454 eligible singleton live births between January 2000 and December 2010, of which 85.5% (7227) had available data on infant HIV status. These reports pertained to 5839 women. Similarly to previous analyses, approximately 90% of births (6429/7227) were to African women. Other demographic and clinical characteristics of the study population are presented in table 5.9.

The overall rate of vertical transmission during the study period was 1.1% (78/7277;

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[151] An infant is “presumed infected” on the basis of one positive PCR result and “confirmed infected” if a further PCR result is positive, or if HIV antibody is detected beyond eighteen months of age. An infant is “presumed uninfected” if a PCR test is negative after one month of age and “confirmed uninfected” after a negative PCR result beyond three months of age or a negative HIV antibody test after eighteen months of age (Townsend, et al. 2008a). For the purposes of this analysis “presumed negatives” were categorised as not infected and “presumed positives” were categorised as infected, as infant status changes rarely unless transmission occurs via breast milk.

95% CI: 0.8%, 1.3%). The vertical transmission rate fell over time from 2.6% in 2000 to a low of 0.3% in 2009 (χ^2_{trend} test $p<0.05$, figure 5.3). The rate increased to 1.3% in 2010 due to time lag in reporting of infant HIV status where infected children are likely to be reported earlier than non-infected infants (Pat Tookey, UCL Institute of Child Health, personal communication, 20 September 2012)[152].

In univariable analysis vertical transmission was associated with lower CD4 count at delivery, shorter duration of ART, preterm delivery and the infant being female[153] (all $p<0.05$, table 5.9). The vertical transmission rate in African women was 1.1% (73/6429) and not significantly different from the rate in white British women (0.6%; 5/848; $p>0.1$, table 5.10). After adjusting for year, duration of ART and CD4 count at delivery African ethnicity was still not a significant risk factor (AOR 2.41; 95% CI: 0.74, 7.85; $p>0.1$, table 5.10). There was no significant difference between rates of vertical transmission among the different African region of birth groups ($p>0.1$, table 5.11) and odds ratios adjusted for year, duration of ART, CD4 count at delivery and infant sex were similar (all $p>0.1$, table 5.11).

Among African women there was a difference in vertical transmission rates according to maternal duration of residence in the UK at conception. The vertical transmission rate in those who arrived in the country after conception was 2.9% (10/347) compared with 1.0% (19/1840) in those who had been in the UK for <4 years and 1.0% in those who had been in the country longer (29/2113; $p>0.1$; table 5.12). After adjusting for year, uptake of ART and CD4 count at delivery, maternal arrival in the UK after conception remained a risk factor, albeit with borderline significance (AOR 2.56; 95% CI: 0.98, 6.68; $p=0.055$; table 5.12).

I hypothesised that the effects of shorter duration of residence in the UK on vertical transmission were mainly mediated by duration of ART and therefore repeated the analysis also adjusting for duration of ART. As expected, maternal arrival in the UK after conception was no longer a significant risk factor for vertical transmission after adjustment for duration of ART (AOR 1.19; 95% CI: 0.43, 3.32; $p>0.1$). This would suggest that the effect of shorter maternal duration of residence was almost entirely mediated by duration of ART.

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[152] Recent analysis of NSHPC data which has more complete information on the infection status of infants has shown a rate of VT of 0.5% in 2010-2011 (Townsend at al.: 2013).

[153] Infant of female sex is a recognised associated factor in the literature (see Chapter Two: 44).

Table 5.9: Characteristics of women with pregnancies reported to the NSHPC by infant HIV status, 2000-2010

	Uninfected, n (row %) n=7199	Infected, n (row %) n=78	*p*-value*
Ethnicity, n=7277			
White British	843 (99.4)	5 (0.6)	0.147
African	6356 (98.9)	73 (1.1)	
Maternal age at delivery, n=7268			
<25 years	1002 (98.7)	13 (1.3)	0.336
25-34 years	4481 (98.9)	51 (1.1)	
≥35 years	1708 (99.2)	13 (0.8)	
Year of EDD/delivery, n=7277			
2000-2003	1645 (98.4)	26 (1.6)	0.016
2004-2006	2541 (98.8)	31 (1.2)	
2007-2010	3012 (99.3)	21 (0.7)	
IDU, n=7277			
No	7125 (98.9)	78 (1.1)	0.368
Yes	74 (100.0)	0 (0.0)	
CD4 count at delivery, cells/µl, n=6349			
≥350	3942 (99.2)	30 (0.8)	0.002
200-249	1684 (99.1)	16 (0.9)	
<200	662 (97.8)	15 (2.2)	
Duration of ART, n=6685			
On ART at conception	1990 (99.9)	3 (0.2)	<0.001
12-40 weeks	2702 (99.4)	16 (0.6)	
2-11 weeks	1648 (98.5)	26 (1.6)	
<2 weeks	126 (93.3)	9 (6.7)	
None	145 (87.9)	20 (1.1)	
Gestation at delivery, n=7176			
≥37 weeks	6236 (99.1)	60 (1.0)	0.019
<37 weeks	864 (98.2)	16 (1.8)	
Mode of delivery, n=7234			
Elective CS	3773 (99.2)	32 (0.8)	0.107
Emergency CS	1654 (98.8)	21 (1.3)	
Vaginal	1729 (98.6)	25 (1.4)	
Sex of infant, n= 7273			
Male	3642 (99.2)	30 (0.8)	0.033
Female	3553 (98.7)	48 (1.3)	

*Obtained using χ^2 test. EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; ART, antiretroviral therapy; CS, caesarean section.

Figure 5.3: Trends over time in vertical transmission of HIV during pregnancy, 2000-2010

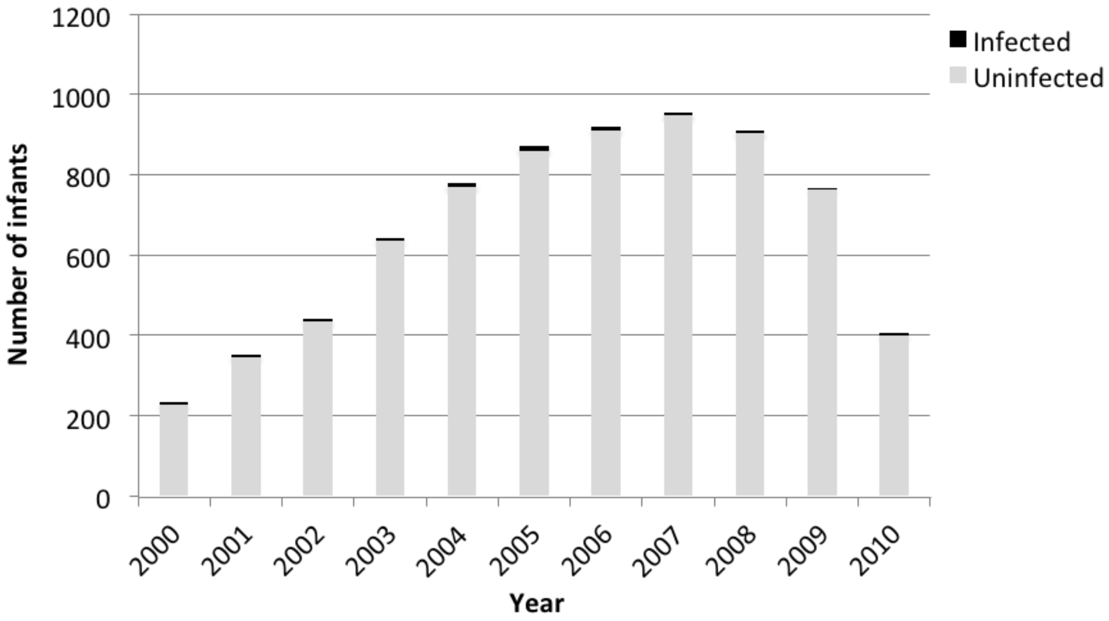

Table 5.10: Univariable and multivariable analysis of the association between ethnicity and vertical transmission of HIV

		Univariable analysis		Multivariable analysis, n=6259	
	VT/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Ethnicity					
White British	5/848 (0.6)	1.00		1.00	
African	73/6429 (1.2)	1.94 (0.78,4.81)	0.117	2.41 (0.74,7.85)	0.145
Maternal age at delivery					
<25 years	13/1015 (1.3)	1.00	0.314		
25-34 years	51/4532 (1.1)	0.88 (0.48,1.62)			
≥35 years	13/1721 (0.8)	0.59 (0.27,1.27)			
Year of EDD/delivery					
2000-2003	26/1671 (1.6)	1.00	0.015	1.00	
2004-2006	31/2572 (1.2)	0.77 (0.46,1.30)		1.16 (0.62,2.17)	0.642
2007-2010	21/3034 (0.7)	0.59 (0.27,1.27)		0.92 (0.46,1.84)	0.807
IDU					
No	78/7203 (1.1)				
Yes	0/74 (0)				
Duration of ART					
On ART at conception	3/1993 (0.2)	1.00	<0.001	1.00	
12-40 weeks	16/2718 (0.6)	3.93 (1.14,13.50)		3.80 (1.10,13.07)	0.034
2-11 weeks	26/1674 (1.6)	10.47 (3.16,34.64)		9.33 (2.76,31.54)	<0.001
<2 weeks	9/135 (6.7)	47.38 (12.67,177.19)		43.94 (11.30,170.83)	<0.001
No treatment	20/165 (12.1)	91.49 (26.87,311.51)		100.12 (26.81,373.91)	<0.001
CD4 count at delivery, cells/µl					
≥350	30/3972 (0.7)	1.00	0.006	1.00	
200-249	16/1700 (0.9)	1.25 (0.68,2.30)		1.20 (0.64,2.24)	0.567
<200	15/677 (2.2)	2.98 (1.59,5.56)		2.82 (1.47,5.40)	0.002

Table 5.10 continued

		Univariable analysis		Multivariable analysis	
	VT/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Gestation at delivery					
≥37 weeks	60/6296 (1.0)	1.00	0.030		
<37 weeks	16/880 (1.8)	1.92 (1.10,3.36)			
Mode of delivery					
Elective CS	32/3805 (0.8)	1.00	0.109		
Emergency CS	21/1675 (1.3)	1.50 (0.86,2.60)			
Vaginal	25/1754 (1.4)	1.70 (1.01,2.89)			
Sex of infant					
Male	30/3672 (0.8)	1.00	0.032		
Female	48/3601 (1.3)	1.64 (1.04,2.59)			

VT, vertical transmission; OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; ART, antiretroviral therapy; CS, caesarean section.

Table 5.11: Univariable and multivariable analysis of the association between African region of birth and vertical transmission of HIV (restricted to African women)

		Univariable analysis		Multivariable analysis, n=5541	
	VT/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
African region of birth					
Eastern Africa	46/3900 (1.2)	1.00		1.00	
Southern Africa	2/492 (2.0)	0.34 (0.08,1.41)	0.138	0.36 (0.08,1.55)	0.170
Western Africa	18/1408 (1.3)	1.08 (0.63,1.88)	0.771	1.04 (0.56,1.92)	0.905
Middle Africa	7/629 (1.1)	0.94 (0.42,2.10)	0.885	0.82 (0.33,2.05)	0.670
Maternal age at delivery					
<25 years	10/770 (1.3)	1.00	0.456		
25-34 years	49/4109 (1.2)	0.92 (0.46,1.82)			
≥35 years	13/1542 (0.8)	0.65 (0.28,1.48)			
Year of EDD/delivery					
2000-2003	24/1448 (1.7)	1.00	0.022	1.00	
2004-2006	29/2292 (1.3)	0.76 (0.44,1.31)		1.05 (0.55,1.99)	0.889
2007-2010	20/2689 (0.7)	0.44 (0.24,0.81)		0.83 (0.41,1.70)	0.611
IDU					
No	73/6426 (1.1)				
Yes	0/3 (0)				
Duration of ART					
On ART at conception	3/1769 (0.2)	1.00	<0.001	1.00	
12-40 weeks	15/2380 (0.6)	3.73 (1.08,12.92)		3.58 (1.03,12.44)	0.045
2-11 weeks	23/1491 (1.5)	9.22 (2.76,30.78)		8.43 (2.47,28.81)	0.001
<2 weeks	9/123 (7.3)	46.47 (12.41,174.02)		42.82 (10.89,168.47)	<0.001
No treatment	19/141 (13.5)	91.68 (26.76,314.09)		114.87 (30.14,437.80)	<0.001

Table 5.11 continued

		Univariable analysis		Multivariable analysis	
	VT/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
CD4 count at delivery, cells/µl					
≥350	27/3422 (0.8)	1.00	0.006	1.00	
200-249	16/1560 (1.0)	1.30 (0.70,2.43)		1.28 (0.67,2.44)	0.444
<200	15/639 (2.3)	3.02 (1.60,5.71)		3.01 (1.55,5.87)	0.001
Gestation at delivery					
≥37 weeks	55/5594 (1.0)	1.00	0.011		
<37 weeks	16/751 (2.1)	2.19 (1.25,3.86)			
Mode of delivery					
Elective CS	30/3303 (0.9)	1.00	0.156		
Emergency CS	19/1511 (1.3)	1.39 (0.78,2.48)			
Vaginal	24/1577 (1.5)	1.69 (0.98,2.89)			
Sex of infant					
Male	26/3227 (0.8)	1.00	0.011	1.00	
Female	47/3198 (1.5)	1.84 (1.13,2.97)		1.96 (1.13,3.42)	0.018

VT, vertical transmission; OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; ART, antiretroviral therapy; CS, caesarean section.

Table 5.12: Univariable and multivariable analysis of the association between duration of residence in the UK at conception and vertical transmission of HIV (restricted to African women)

		Univariable analysis		Multivariable analysis, n=3922	
	VT/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Duration of residence in UK					
≥ 4 years	20/2113 (1.0)	1.00		1.00	
< 4 years (before conception)	19/1840 (1.0)	1.09 (0.58,2.06)	0.780	1.30 (0.63,2.65)	0.478
Since conception	10/347 (2.9)	3.11 (1.44,6.69)	0.004	2.56 (0.98,6.68)	0.055
Maternal age at delivery					
<25 years	8/511 (1.6)	1.00	0.593		
25-34 years	31/2747 (1.1)	0.72 (0.33,1.57)			
≥35 years	10/1038 (1.0)	0.61 (0.24,1.56)			
Year of EDD/delivery					
2000-2003	16/974 (1.6)	1.00	0.171	1.00	
2004-2006	18/1533 (1.2)	0.71 (0.36,1.40)		1.05 (0.47,2.35)	0.909
2007-2010	15/1789 (0.8)	0.51 (0.25,1.03)		0.92 (0.39,2.15)	0.841
IDU					
No	49/4295 (1.1)				
Yes	0/1 (0)				
Uptake of ART					
Yes	37/4168 (0.9)	1.00	<0.001	1.00	
No	12/94 (12.8)	16.34 (8.22,32.47)		18.24 (7.34,45.29)	<0.001
CD4 count at delivery, cells/µl					
≥350	16/2385 (0.7)	1.00	0.009	1.00	
200-249	14/1114 (1.3)	1.88 (0.92,3.87)		1.94 (0.93,4.02)	0.077
<200	10/423 (2.4)	3.59 (1.62,7.95)		3.41 (1.51,7.71)	0.003

Table 5.12 continued

		Univariable analysis		Multivariable analysis	
	VT/N (%)	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Gestation at delivery					
≥37 weeks	38/3777 (1.0)	1.00	0.026		
<37 weeks	11/480 (2.3)	2.31 (1.17,4.55)			
Mode of delivery					
Elective CS	20/2156 (0.9)	1.00	0.202		
Emergency CS	11/1032 (1.1)	1.15 (0.55,2.41)			
Vaginal	18/1089 (1.7)	1.79 (0.95,3.41)			
Sex of infant					
Male	18/2161 (0.8)	1.00	0.054		
Female	31/2132 (1.5)	1.76 (0.98,3.15)			

VT, vertical transmission; OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; ART, antiretroviral therapy; CS, caesarean section.

5.5 Summary of epidemiological analyses

I have found no evidence of an association between ethnicity and uptake of ART in pregnancy, detectable HIV viral load at delivery and vertical transmission. This is consistent with previous studies (Mayaux et al. 2003, Jasseron et al. 2008, Townsend et al. 2008a, Floridia et al. 2010, Izzo et al. 2011, Modestini et al. 2012). However, I have found disparities *among* African women. Western African women were more likely not to receive ART in pregnancy than women from Eastern Africa, although it is important to remember that this is a very small proportion of Western African women (3.5%). They were also more likely to have declined ART in pregnancy, along with those from Middle Africa.

The most striking differential was among women who had arrived in the UK *after* conception when compared with those who had been in the UK for those who had been in the UK for four years or longer[154]. Women who had arrived in the UK after conception were twice as likely to *not* receive ART in pregnancy, to have a detectable HIV viral load at delivery and to transmit HIV to their infants[155].

5.6 Ethnographic data

The quantitative results I have presented provide us with some useful entry points into the complexities of ART use during pregnancy. The overwhelming majority of women living with HIV (regardless of ethnicity, country of origin or duration of residence in the UK) take ART during pregnancy, mainly successfully, with 80% achieving virological suppression at delivery and very few instances of transmission to infants, suggesting both that women generally adhere to prescribed ART, and that it is effective.

But what of the small numbers of women who don't receive ART? It seems unlikely that healthcare professionals would limit access to ART in certain groups of pregnant women given that treatment is advised for *all* HIV-positive women in pregnancy. I

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[154] The high proportion of missing data on maternal duration of residence in the UK raises concerns about bias. However, reassuringly the proportions of women who did not receive ART during pregnancy, who had a detectable viral load at delivery and whose pregnancy resulted in an infected infant were similar in the groups with and without data on maternal duration of residence (all $p>0.1$).

[155] When adjusting for duration of ART, the association between duration of residence in the UK and detectable viral load at delivery was attenuated but remained statistically significant. This was not the case for the association between vertical transmission and duration of residence in the UK, which was no longer significant after adjusting for duration of ART. This difference is likely to be due to the very small numbers of infected infants in the dataset and the limited power to detect differences in analyses of vertical transmission. It may also suggest that the effect of shorter duration of residence on vertical transmission was mediated entirely by duration of ART, whereas the effect on viral load at delivery may be more sensitive to other factors such as adherence (even in the absence of ART the risk of vertical transmission is 25% whereas poor adherence often leads to virological failure).

am particularly interested in why Western African women were most likely *not* to receive ART during pregnancy (with over a third of those not receiving ART declining treatment), although I am mindful that this represents a very small number of women. Furthermore, the quantitative results prompt us to ask why African women who migrate to the UK during their pregnancy are more likely to exhibit poor use of ART as evidenced by the increased likelihood of not receiving treatment, and increased rates of detectable viral load at delivery and vertical transmission[156]. Although biological differences, such as pharmacokinetics and drug resistance, cannot be discounted it seems unlikely that that these would be the mechanisms by which duration of residence in the UK would lead to differentials in virological suppression.

For the remainder of this chapter I will draw upon data from my ethnographic research to tease out the complex processes involved in taking, or not taking, ART during pregnancy. Specifically, I will explore what enables the overwhelming majority of women to take ART during pregnancy, and what may underlie the disparities identified in West African women and women who migrate to the UK during pregnancy.

5.6.1 The notion of compliance

Within biomedical discourse, to take ART as prescribed is to *adhere* to ART. As discussed earlier, *adherence* is closely related to the notion of *compliance,* albeit with a subtle nod to issues of agency and choice. Whatever the distinctions, both concepts concern the degree to which a patient follows medical advice. Traditional sociological critiques of compliance have emphasised the negative consequences of biomedical authority in either constructing an ideology of compliance where non-compliance is seen as deviant (Trostle 1988) or failing to acknowledge other aspects of experience that may inform a person’s decision to take medication (Conrad 1985). Inherent in these critiques is the desire to decentre biomedical perspectives, and instead foreground the views of patients.

This body of work has been important in reframing notions of compliance to take into account patient agency. However, the preoccupation with biomedicine[157] as a

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[156] I have shown earlier in this chapter that the increased risk of vertical transmission in this group is likely to be due to shorter duration of ART and the consequent risk of lack of virological suppression by delivery.

[157] I use the term biomedicine to refer to systems of healing that are derived from biological and natural sciences. Other systems of healing may include complementary medicine, traditional medical practice and religious healing.

repressive regime[158] may limit analytic engagement with compliance as it pertains to the realities of living with HIV in the twenty-first century (Mykhalovskiy et al. 2004)[159]. The somewhat myopic view of compliance as patients being compelled to follow medical advice tends to privilege *non-compliance* as the object of interest, taking as its departure point an assumption that not taking medication is an act of agency. Whilst this may be true, what is missing from this argument is a consideration of the reasons why patients may *want* to take treatment. Furthermore these older critiques of compliance tend to focus on either doctors or patients (or both), and originate in an era which predated the global commodification and popularity of biomedicine and the plethora of extra-clinical sites where medical knowledge is constructed (Mykhalovskiy et al. 2004).

As an HIV clinician, I have seen at first-hand how ART has radically transformed the lives of people living with HIV, affording near-normal life expectancy in a state of good health. The AIDS-ravaged bodies that populate the ethnographies of Paul Farmer in Haiti (2004) and Didier Fassin in South Africa (2007) have rarely been a feature of my work due to the widespread availability of ART in the UK. The potential of ART to transform lives is perhaps nowhere more evident than in pregnancy. Where once HIV-positive motherhood was plagued by the agonies of vertical transmission and death, ART's impact on maternal health and the prevention of vertical transmission has now fostered a sense of optimism and hope. However ART is not without its constraints, requiring commitment to a daily (and sometimes complex) medication regimen and the acceptance of possible side effects. The consequences of poor adherence to medication are progression of HIV disease, the development of ART resistance and, in the case of pregnancy, vertical transmission. It is therefore unsurprising that adherence is a focal point of interest in clinical practice. Certainly in most departments I have worked, weekly meetings have been set aside for the sole purpose of discussing why patients are "failing"[160] on treatment, with lengthy explorations of patients' adherence "issues". Although the language of failure may at first suggest a framing of non-compliance as

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[158] This argument is mainly informed by Foucault's genealogy of modern medicine in which he traces the diffuse power that underpins the construction of the human body as a 'knowable' site by experts (doctors) (Foucault [2003] 1963).

[159] In their work on the use of ART by people living with HIV in Toronto in the late 1990s, Mykhalovskiy et al. reveal that adherence is not an example of biomedical disciplinary power; rather it is a complex technology that is constructed in multiple interlocking sites both within and outside of the clinic. Furthermore, the authors describe how healthcare professionals and biomedical researchers actively engage with the social reasons behind poor adherence and seek to individualise treatment in order to enable their patients to take their medication effectively, rather than compelling them to comply.

[160] Failure in this context means that a patient on treatment has a detectable viral load.

deviance, my experience does not bear this out. Clinical discussions about adherence are predominantly multidisciplinary (comprising doctors, nurses, pharmacists, psychologists and social workers) and are multi-dimensional, engaging with a wide range of possibilities ranging from side effects to interactions between staff and patients to a patient's health beliefs. These discussions rarely blame patients, and instead focus on ways to work with individual patients to understand why adherence may be challenging. Some patients may be reluctant to take ART for a variety of reasons and these views, although as a clinician sometimes hard to accept, are generally respected. In contradistinction, treatment is rarely withheld from those who require it and wish to take it[161].

Therefore, we can see that in order to understand adherence to ART during pregnancy, we need to broaden discussions beyond *non-compliance* and the disciplinary power of doctors and engage with the possibility that patients wish to take medication and that constraints may lie both within and outside the domain of biomedicine.

5.6.2 Antiretroviral therapy as a generative tool

Motherhood plays a central role in the lives of many African women living with HIV in the UK, whether they have a child or not. Smith and Mbakwem (2007) discuss the cultural imperative in Nigeria to have children, describing how childbearing is seen as a fundamental contribution to community. In Whyte's ethnography of the management of misfortune by the Nyole in Eastern Uganda (1997), one of the greatest misfortunes is infertility:

> "An individual is not a complete social person until he or she is married and can begin the process of forming a new household."
>
> (Whyte 1997: 54)

In each of these contexts, parenthood is a social requirement. It is intrinsic to one's transition into adulthood and fulfils an important role in the flourishing of society; a social and biological reproduction.

African women feel the weight of this expectation, even having moved to the UK.

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[161] A recent amendment to the Health and Social Care bill, which came into effect from October 2012, has overturned previous legislation that instructed the withholding of free HIV treatment from non-UK citizens and undocumented migrants. In practice, this was rarely enforced by clinicians, although not openly discussed (Department of Health 2012a) .

Living in the transnational space of diaspora does not erase internalised cultural expectations of motherhood. Close links to African kin and communities, both within the UK and abroad, reinforce the need to fulfil one's role as a woman by becoming a mother. Procreation was a central preoccupation at the Pentecostal church in which I conducted fieldwork with large sections of services appealing to the Lord to bless the congregation with "fruits of the womb"[162]. Many African women living with HIV share this similar cultural universe with regards to procreation. Being childless is greeted with suspicion, with women held accountable in the earthly and spiritual realms as described by the following participant:

> *They think you're barren [...] you're wild, you dress improperly, you party, you've had relationships. They will think all of that. If a person has been having problems of her womb [...] they have also a lot of stories behind it [...] they can even call you [a] witch.*
>
> (Stella)

Many women, when discussing their initial response to their HIV diagnosis, talked of how it had symbolised the end of their life. Most had migrated from settings where ART was not widely available. They had seen, or at least heard of, family and acquaintances die of AIDS-related illness. Prior to their diagnosis, few had seen women with HIV become mothers. Being HIV-positive in the UK afforded them access to ART and a chance to live, both biologically and socially. ART therefore becomes an important route through which to achieve a culturally prescribed female identity, and it was no surprise that all the pregnant women I encountered had taken or were taking ART[163]. It allowed them to entertain the possibility that they might survive, be healthy and produce a healthy child. Smith and Mbakwem (2007), in their study of adults receiving ART in Southeastern Nigeria, write of the importance of ART in people's "life projects"; that is, in a life that is expected to be defined by marriage and childbearing, ART becomes a means of achieving normality. ART allowed many of my participants to fulfil their "life project" to become a mother, avoiding the stigma of being a childless woman and suspicion as to the reasons why. It allowed them to "pass" as though they were HIV-negative (Goffman [1990] 1963).

However, women were not merely performing to cultural scripts. As in previous studies

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[162] This is discussed in greater detail in Chapter Six.

[163] Of course, this is a self-selecting sample of women who were engaged in HIV antenatal care at NHS clinics or HIV support services. Women who were poorly engaged with care, or who did not wish to take ART, were unlikely to consent to participation.

from the US (Richter et al. 2002, Sandelowski et al. 2003, Kirshenbaum et al. 2004, Sanders 2008), pregnancy frequently gave women a renewed sense of purpose and meaning in their lives in the wake of an HIV diagnosis. Femi, who was expecting her first child, expressed the heightened importance of becoming a mother after receiving her HIV diagnosis a year earlier, framing motherhood in terms of legacy:

Being HIV positive, you just have this impending feeling of doom and then you're also like 'OK, I need to have something of myself still remaining on this earth before I go'.

(Femi)

For others, their diasporic journey had been characterised by loss and exile. Many had left children behind with family as they forged new lives in the UK. Some had maintained contact by telephone or internet, but the constraints of poverty or their immigration status prevented them from being able to be with their children. Furthermore, their HIV diagnosis was a further barrier due to anxieties about access to ART in their home countries. In an unenviable double bind, a new baby provided some balm and an opportunity to mother again. For others, the situation was even starker. Mariama had fled Guinea due to political persecution, having been subjected to extreme physical and sexual violence in a military prison. She had been smuggled out of the country by a friend, leaving her seven-year-old son with her parents. She no longer knew their whereabouts. The promise of a new baby provided some degree of consolation:

That's why when I was pregnant I was praying to God, like God give me a boy again because I miss my son so much. It helps me think about my son, when I see him I think like I'm seeing another one. [It makes me] very happy.

Sandelowski (2003), in a metasynthesis of qualitative work in the US, divides the "work" of motherhood in the context of HIV into two domains. The first pertains to the preservation of a positive maternal identity. Thus far, I have explored how this is specifically elaborated within an African diasporic setting in the UK. The second domain refers to the protection of the child from HIV. Every woman in my study cited this as the most important motivation in taking ART during pregnancy, even if some had been reluctant to take ART or poorly adherent prior to their pregnancy. Many could not understand why a woman would not take ART during pregnancy:

They maybe don't cherish what is in their belly. You have to cherish your baby. Because right now, the baby's innocent. You can't transfer your sickness to the baby, you have to take it.

(Effia)

ART is imbued with affective properties. It is a vehicle by which you can "transfer" love to your baby, ensuring their health. The assumption is that by not taking ART, you fail to protect your baby, "spoiling" your identity as a good mother. The many conversations I have had with clinical colleagues over the years, as a clinician and as a researcher, serve to underline this. Women who do not take ART during pregnancy, or who do not have good adherence, are of particular concern to the clinical team, mainly because of the risk of vertical transmission. The situation provokes a great deal of anxiety and often results in intensive monitoring of the mother's clinical situation and further discussions about the risk a woman may pose to her child in other ways such as withholding ART prophylaxis from the baby after delivery or breastfeeding.

ART therefore serves multiple functions in the context of maternal HIV infection. Beyond its pharmacological actions in sustaining a woman's health and preventing vertical transmission, ART has important transformative powers (Whyte et al. 2002)[164]. Antiretrovirals can be seen as "potent symbols and tokens of hope" (Ibid.: 5), providing the means to generate a positive identity as a fully-fledged adult, as a woman, and as a good mother.

5.6.3 Illness within a healthscape

The dichotomy between 'Western' and 'non-Western' medical systems looks increasingly tenuous in a globalised world. Medical technologies have widespread purchase and the $300 billion global pharmaceuticals market[165] is evidence of the unbridled commodification of medicines. Biomedicine is now widely accepted throughout the world. It is seen as effective, especially in areas of high morbidity and mortality where antibiotics and vaccination have had a tangible effect on people's lives. It also has many practical advantages such as ease of access and not requiring the significant degree of interpersonal effort required in other systems such as divination

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[164] Susan Whyte and colleagues describe the key features of medicines as including the "powers to transform…they are supposed to do something, to change the body in a discernable way" and that these "transformative powers can be put to different purpose" (2002: 5).

[165] See http://www.who.int/trade/glossary/story073/en/index.html (accessed 15 September 2012).

(Whyte 1997)[166]. Furthermore, it carries prestige due to its association with “powers of modernity, distant centres of advanced technology, and professional expertise” (Ibid.:229). Biomedicine has demonstrated great capacity in penetrating other medical systems. In many settings, traditional medicines have been transformed from outdated preparations to hi-tech coated tablets in blister packs, emulating biomedicine in an effort to compete in the medicine market (Cocks et al. 2000, Bode 2006). Biomedicine’s widespread popularity and success in penetrating markets and other medical systems makes it an exemplar of globalisation. It is difficult to know where to situate medical systems within Appadurai’s "-scapes" described in Chapter One as they largely incorporate aspects of technology, finance, information and ideology (1996). To this end, I offer the neologism *healthscape* in an attempt to capture the transnational flow of medical knowledge (not just biomedical) and technologies. As in Appadurai’s “ethnoscapes” and “financescapes”, healthscapes are multiperspectival and globally connected, with specific local articulations.

The African women in my study exist within a healthscape where biomedicine is not an alien technological innovation. This is partly because they are predominantly a group of well-educated women who have come from affluent and urbanised backgrounds in Africa. Hospitals were described as relatively easy to access at home in Africa, and their status as members of the elite frequently meant that they would preferentially seek hi-tech and modern interventions[167]. All the women I interviewed had experience of biomedicine in Africa prior to migration, and many described previous pregnancies where they had delivered in hospitals in their home countries. Some travelled regularly between their African and London homes and therefore experienced biomedicine much more directly as an interconnected space. For example, Effia had been diagnosed with HIV during her pregnancy when she had attended an antenatal clinic in Ghana with fevers, and was promptly commenced on ART. Shortly after, she left Accra to join her husband in London as they both felt that she would receive more specialised care in the UK. As it transpired, Effia’s doctors in London did not make any changes in her medication. She felt that the clinic in London was more efficient, respected her confidentiality and gave her access to free ART, but these operational differences in local systems did not detract from Effia’s overall experience of HIV medicine as a

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[166] In her work on how misfortune is addressed in Eastern Uganda Whyte contrasts divination, with its reliance on complex negotiations between kin, with other remedial measures such as biomedicine that require less interpersonal effort.

[167] My questions on the use of traditional or herbal medicines whether in the UK or Africa, were often greeted with bewilderment or mild exasperation; a salutary lesson on my own ethnographic naivety.

transnational interconnected practice. For many women, their diasporic vantage point within the healthscape gave them an acute awareness of the differences in biomedical systems between *here* and *there*:

> *I have to take this opportunity though. There are other people in our countries or in other countries; they're dying without [ART].*
>
> (Marie)

Although other authors have documented gratitude as a motivation for taking ART in pregnancy (Doyal et al. 2005, McDonald et al. 2011), my participants' views of ART as opportunity were uniquely shaped by living in diaspora. Many had come from, and maintained strong links with, settings where ART was not widely available, having borne witness to countless AIDS related deaths as a result of the global inequities in ART distribution[168]. With this in mind, women felt that access to ART in the UK provided them with an opportunity that must be grasped.

So, for these women, biomedicine was an important and familiar resource. When discussing their condition, they often employed biomedical terms in lengthy explanations about the importance of the "immune system", "CD4 counts", "levels of virus" and being "undetectable"[169]. However, far from being a model imposed on women by staff at their clinics, the construction of the HIV-positive body as a biological body was also shaped by women's interactions with electronic media, when looking for information on ART and HIV in pregnancy, and extra-clinical sites such as Body & Soul[170]. It is also important to note that, according to UK surveillance data[171] and my ethnographic data[172], the majority of women living with HIV who become pregnant are diagnosed with HIV prior to their pregnancy. Having often lived with HIV for some time, many were well versed in biomedical understandings of HIV and the body.

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[168] Although ART coverage for the prevention of vertical transmission in Sub-Saharan Africa has increased significantly from 15% in 2005, it remained 41% in 2010 with coverage in West and Middle Africa reported to be 27% (UNAIDS 2011).

[169] As I demonstrate later in this chapter, this does not mean that women don't retain co-existing models of illness.

[170] Common workshop themes included modes of action of ART and the interpretation of HIV blood test results. These sessions were often extremely popular with members who were eager to learn about HIV and new developments of medication. In fact, the only workshops that rivalled these in popularity were the ones that addressed disclosure of HIV status to sexual partners, suggesting that understanding the biological processes of HIV and finding a way to be HIV-positive in a relationship were central concerns for people living with HIV.

[171] See Chapter Four (table 4.6: 109).

[172] See table of participant characteristics (Appendix v).

These women were therefore oriented towards a biomedical system, at least in terms of HIV and pregnancy, and were willing to engage with clinical staff. In each of the three hospitals, women received HIV care during pregnancy from a team that included, at the very least, a HIV specialist doctor and midwife. They were reviewed in pregnancy at least once a month (which is more frequent than outpatient appointments in adults who are not pregnant) and may have up to a few hours at a time with various members of the clinical team. Contrary to my expectations, most women did not find the increased frequency and duration of appointments intrusive. Most described the care they received from their HIV clinical team during pregnancy in positive terms, valuing the time they had been given to have treatment explained and their concerns about side effects and toxicity addressed. They also appreciated the continuity in their care as, rather unusually for current antenatal care in the UK, they were able to see the same midwife and clinician at each visit. Engagement with a core group of specialist and highly experienced staff over regular appointments, fostered relationships with doctors and midwives that were founded upon trust and confidence, resulting in women feeling reassured about taking ART during pregnancy.

Relationships with the HIV antenatal team were generally imbued with affective properties that defined how women saw their interactions with staff, many recalling names of key healthcare professionals they had met in previous pregnancies with a couple of women discussing how they had “followed” their HIV doctor to another unit when they had transferred to another job. Many women saw their relationships with the HIV team as being characterised by *care* on a more holistic level. They described being supported not only with clinical aspects of HIV and pregnancy, but emotionally and socially in terms of practical assistance with money, housing and immigration. In the 1980s, Cecil Helman highlighted the importance of context in doctor-patient consultations, describing how the course of illness was often shaped by factors outside the consultation room (Helman 1984). More recently, Anne-Marie Mol has framed this philosophically within what she terms the “logic of care” (2008). Mol contrasts the logic of care with its hegemonic counterpart, the “Logic of Choice” which constructs patients as individual consumers who must make their own choices about their health and take responsibility for poor decisions. The logic of care, on the other hand, understands that people do not experience illness as individuals, may find choice in the context of distress challenging, and may be constrained by a variety of factors in their ability to exercise their choices. Within the logic of care, healthcare professionals work flexibly with patients to find ways in which they can live with illness better. It is:

“A language in which the main emphasis is not on autonomy and the right to decide for oneself, but on daily life practices and attempts to make these more liveable through inventive doctoring. In care-specific terms, care is bad when people are being neglected. When there is not enough time to listen. When physical parameters are isolated from their context; when patients’ daily lives are not taken into consideration.”

(Mol 2008: 84)

In the strong relationships forged between professionals and patients, and staff’s willingness to engage with the realities of women’s lives, we can see evidence of the logics of care operating within the HIV antenatal clinic and acting as an enabling factor in adherence to ART:

Everybody takes care of you; they smile at you all the time [...] it gives you more power to come again to take your medication.

(Fatima)

5.6.4 The work of ART

Although all the women I interviewed took ART during pregnancy, for many this presented a number of challenges. Very few reported that this impacted on their adherence; yet I knew from discussions with healthcare professionals that a number of them had not achieved virological suppression, suggesting poor adherence. Opening up a conversation about poor adherence with pregnant women proved to be very difficult. This can perhaps be better understood if we recall the complex ways in which taking ART in pregnancy is bound up with the generation of a positive identity as both a woman and mother. It also suggests that despite the good relationships that are forged within the HIV clinic between staff and women, there remains a power structure in which women feel they may be ‘disciplined’ by staff for “failing” on ART.

Conrad’s seminal study of compliance in the context of epilepsy (1985) highlights the analytic limitations of attributing poor compliance solely to doctor-patient interactions or patient’s health beliefs, emphasising the importance of engaging with adherence in the context of patient’s lives. Many women experienced nausea, vomiting, fatigue and abdominal pain. In pregnancy it was often hard for women and their healthcare professionals to distinguish whether these symptoms were due to pregnancy or side effects of medication. These bodily symptoms were a source of great anxiety, with many women acutely aware of the need for excellent adherence to minimise the risk of vertical transmission:

> *It's really really hard because you get heartburn with pregnancy itself so when I take my medication it comes out and I struggle to take more. Before I was pregnant and I was taking medication there was never any problem [...] It stressed me out because if the medication comes out then my CD4 and viral load will be up and I thought 'Oh my God, it's going to hurt the baby if I'm not taking my medication properly.'*
>
> (Mehret)

For others, the presence of side effects was a sign that ART could be harming their baby. Although on the whole women felt reassured by their doctors and midwives who emphasised the low risk of toxicity of ART to their baby, many described a residual anxiety about the potential for the medication to cause harm. For them, ART was an ambiguous substance with beneficial and toxic properties; a *pharmakon*[173] capable of preventing vertical transmission but also of causing damage to their unborn child. This is hardly surprising given that most pregnant women, outside the context of illness, are advised to avoid medication and are heightened to the possibility of noxious substances that could harm their baby whether it is alcohol, food, or cigarettes[174].

Another theme that emerged was that of experimentation, in that some women felt that staff were not certain about drug dosage or efficacy and had to 'experiment' to find the correct regimen. This fear is not unfounded given the history of unethical HIV-drug trials in pregnancy across Africa in the 1990s (Fassin 2007)[175] and that the only licensed

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[173] The word pharmaceutical, as highlighted by Derrida (1981), derives from the Greek *pharmakon* which has a dual meaning as both remedy and poison.

[174] See the recent paper published on behalf of the Royal College of Obstetrics and Gynaecology, which warns expectant mothers of the risk of exposure to a host of commonly encountered household chemicals (Royal College of Obstetricians and Gynaecologists 2013). This is discussed in greater detail in Chapter Eight.

[175] Fassin traces the long history of unethical research practice during the HIV epidemic in Africa. Specifically in the context of pregnancy, fifteen of sixteen studies investigating the prevention of vertical transmission, most funded by the United Sates National Institute of Health but conducted within Sub-Saharan Africa, used a placebo-group when trialing new agents in pregnancy despite evidence of the efficacy of zidovudine in preventing transmission in the landmark ACTG076 trial. During the same time period, studies conducted in North America did not use a placebo arm, instead giving control groups zidovudine. These early studies in Africa deliberately exposed children to the natural risk of HIV infection in the quest for achieving results as fast as possible (Fassin 2007: 90).

antiretroviral medication in pregnancy is zidovudine[176]. The overriding concern for most women was that ART would result in physical deformity meaning that foetal ultrasound imaging took on particular importance:

Before I was HIV-positive I never really cared. I just wanted to look at how the baby moved. But now I read everything in detail. Normal heart, legs, skin…and I make sure that all those parts are normal because now I am more paranoid. It's like a reassurance that there's one worry that is taken out.

(Faith)

Other authors have charted the rise of foetal ultrasound use in pregnancy and its role in constructing a 'knowable' pregnant body and reinforcing the clinical gaze (Shaw 2012)[177]. Ultrasound imaging has become the norm during pregnancy in hospital settings and is popular among pregnant mothers, partly due to its symbolic association with technological modernity and expertise, and also the currency of the visual image in contemporary culture (Georges 1996). For women who have HIV, ultrasound scanning carries extra salience; they are exposing their babies to medication that they fear may cause physical deformity to their baby. This (coupled with a constellation of symptoms that might be due to pregnancy, to ART, or to HIV), results in women mistrusting their own readings of their pregnant bodies. The combination of HIV, ART and pregnancy have rendered their bodies unreliable, laden with symptoms and signs that need to be monitored, interpreted and scanned by medical experts.

We know that the management of chronic illness entails management and "work" (Corbin et al. 1985, Sandelowski et al. 2003). The women in my study engaged in *antiretroviral work*; struggling to take ART in the face of mysterious symptoms, fears about toxicity, fears that ART may not be effective and mistrust of their own bodies. An ultrasound image of a healthy baby and the safe arrival of their child went some way to providing relief but these fears often continued until the final confirmation that their baby was HIV-antibody negative at eighteen months of age. Others remained anxious and guilty that illnesses their children developed as they grew older were due to *in-utero* exposure to ART, demonstrating that antiretroviral work is not a time-bounded

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[176] There is a global consensus that other antiretroviral medications are safe in pregnancy among HIV professionals, however pharmaceutical companies have not obtained licenses for use in pregnancy due to logistical difficulties in running clinical trials in pregnant women and cost implications.

[177] Again, these critiques are heavily influenced by the work of Foucault on the development of modern medicine and its construction of the body as a site of knowledge and power (Foucault [2003] 1963).

phenomenon but a process that extends beyond pregnancy far into motherhood.

5.6.5 Bare lives

One of the most pervasive barriers to the uptake of treatment is stigma. HIV has culturally been constructed as a highly stigmatising condition due to its association with non-normative sexuality, perceived aberrant behaviour, infectiousness and death. Goffman defines stigma as an “attribute that is deeply discrediting” ([1990] 1963). My fieldwork revealed that many Western Africans felt that HIV-related stigma was more pronounced within their communities than other African communities

> *The funny thing in Africa, especially in my country [Guinea], is that when they know you have this, even your baby can’t come close to you. It’s not like in Uganda, or in the rest of East Africa, because they know there 80% are in this situation – but in West Africa, there are not a lot of people who have it. So when you have it you can’t have anyone that come close to you. Even your mum, or your brother, or your sister, or your kid, no one will come close to you.*
>
> (Mariama)

HIV-related stigma is a product of cultural, historical and socioeconomic factors. Genberg et al (2009) have found an association between lower prevalence of HIV and higher levels of stigma and discrimination. Higher levels of stigma were also reported in countries with lower nationwide coverage of ART (Ibid.)[178]. Lower prevalence results in less contact and experience of those living with HIV, and less opportunity to develop a sense of normality regarding HIV. In low prevalence settings HIV may also be concentrated in certain minority groups, prompting people to link HIV with stigmatising characteristics found within these groups. Furthermore, the lack of a visible ART programme reinforces the belief that HIV is an invariably fatal disease (Genberg et al. 2009). In this context, stigma flourishes[179].

HIV often carries no visible stigmata, allowing people to pass as HIV-negative should they wish to. Much work is involved in managing information in order to present an

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[178] Of note, the prevalence of HIV in Nigeria was estimated to be 3.7% in 2011 compared with 7.2% in Uganda and 17.3% in South Africa. Country specific estimates obtained from http://www.unaids.org/en/regionscountries/countries/ (accessed 23 September 2013).

[179] Two studies each from different regions of Nigeria have highlighted the coupling of HIV and pessimistic outcomes and the particular prominence of moralising discourses on HIV, suggesting that this is due to a combination of lower prevalence rates (Winskell, et al. 2011) and the widespread influence of Evangelical Christianity (most notably Pentecostalism) which constructs HIV as divine punishment for sin (Smith 2003).

HIV-negative self, thus avoiding a potentially discreditable attribute from becoming discrediting. Coming to hospital for appointments, storing and taking medication and possible side-effects of ART (such as rashes) can compromise women's work in trying to pass as HIV-negative. Their fears about disclosure were well founded given the many instances I came across of discrimination, abandonment, and emotional and physical abuse. This work in presenting an HIV-negative self was further complicated by structural factors experienced as a result of migration such as inadequate housing, which meant that many women were sharing living spaces with family members or strangers and had limited space to be able to store and take ART in privacy.

The daily work of taking ART was even more pronounced for those with insecure immigration status[180]. We have already seen in the analysis of surveillance data that women who arrived in the UK during their pregnancy were at higher risk of not taking ART, having a detectable viral load at delivery and transmitting HIV to their baby. New migrants are notably under-represented in my fieldwork[181], however ten of the twenty-four women I interviewed reported that they had insecure immigration status. Their experiences are likely to be shared by many women who have recently arrived in the UK (who often also have insecure immigration status) and are therefore illustrative.

Within this group of women, destitution and food insecurity were part of everyday life, many of them unable to work due to restrictive immigration policies[182]. On an instrumental level, lack of food made taking ART very difficult as it resulted in women experiencing nausea and abdominal pain. Women's lives were dominated by their immigration status and the consequential poverty and housing crises that this brought. Some had been housed by the National Asylum Support Service[183], however this accommodation was often temporary and of poor standard. Others were forced to depend on friends, family and sometimes violent partners, setting in motion a chain of further vulnerability. In this context of chronic and extreme material insecurity, HIV

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[180] Secure immigration status is defined as being a UK citizen, a recognised refugee or having exceptional or indefinite leave to remain. Anyone not in these categories is defined as having insecure immigration status.

[181] I was only able to interview one woman who had arrived in the UK after conception, partly a reflection of the general trend towards longer duration of residence at conception (Chapter 4: figure 4.4: 103) and also the fact the women who arrived in the UK after conception often presented late in pregnancy and were newly diagnosed with HIV, and therefore not in a position to participate in a study.

[182] Since 2002 asylum seekers have been denied the right to work unless they have waited for over twelve months for an initial decision regarding their asylum application. People who have been refused asylum (after appeal) and those who are in the UK without any documentation have no permission to work legally (see http://www.parliament.uk/briefing-papers/SN01908, accessed 22 July 2013).

[183] The section of the UK Border Agency which is responsible for supporting and housing asylum seekers whilst a decision is being made about their asylum application.

and ART fall lower and lower in a woman's "hierarchy of needs" (Maslow 1943)[184]. Their suffering was compounded by fears of compulsory dispersal to other areas of the UK and being removed from what little support network they may have, and fears of being deported back to Africa where access to ART remains uncertain in many settings. Even within the UK, women's access to ART was far from guaranteed with one woman having been sent hospitals bills of over £20,000 for her treatment during pregnancy[185]. Add to this the likelihood that for women who have recently arrived in the UK their HIV diagnosis is new, and the situation soon becomes intolerable. One woman was uncompromising in her assessment:

the ones with [secure immigration] status live longer than the ones without.

This complex set of factors that constrain some women's access to care or uptake of ART encapsulates Galtung's concept of structural violence (1969)[186]. The forces of poverty, inadequate housing, gender inequality and immigration law combine and become embodied by women through disparities in engagement with HIV care (Farmer et al. 2006)[187]. Building upon Famer's work on structural violence and HIV, I want turn to the Italian philosopher Giorgio Agamben (1998) and his use of the Roman figure of law *Homo Sacer*[188]. Political institutions have biopolitical power to create subjects who are neither human nor divine, their lives without worth and at risk of being killed with impunity (akin to *Homo Sacer*). Those who reside in this "zone of indistinction [are] between man and beast, nature and culture" (Ibid.: 109)[189]. They are reduced to a "bare

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[184] This is highlighted by a recent systematic review of housing status and the health of people living with HIV (Aidala, et al. 2012).

[185] This was in direct contravention of UK law, which stipulated that all pregnant women receive free HIV treatment as part of "immediately necessary" maternity services to prevent vertical transmission (Department of Health 2010).

[186] In Chapter One I introduced the concept of structural violence as a theoretical frame for this thesis.

[187] Of interest here is Catherine Kingfisher's work on the gendering of welfare decline in the West (Kingfisher 2002). Within the contemporary neoliberal economic landscape, those who cannot work and participate in the public realm of the marketplace (such as single mothers) are stripped of personhood and deemed "normative strangers" (Ibid. 22). State welfare institutions and discourses surrounding them serve to police these boundaries, often reinforcing subjugated positions. In the same edited volume Ruth Lister (Ibid.) traces the emergence of "problem" lone mothers in the UK from the Thatcher-era to the New Labour project. Lister describes lone mothers as a "lightening conductor for a number of political concerns centering on family "breakdown", gendered labor market trends, "welfare dependency", and welfare spending"" (Ibid.: 127). Post New Labour and in the age of austerity, I would argue that the prominent anti-immigrant rhetoric that dominates contemporary British politics is evidence that immigrants, especially asylum seekers, have now assumed a similar role.

[188] The accursed man who may be killed, without the killer being seen as a murderer, but not sacrificed. *Homo Sacer* is a figure that stands apart from society, disinvested of civic rights.

[189] See also Joao Biehl's "zones of social abandonment" in his ethnography of Vita, a Brazilian asylum for abandoned people which includes those with mental illness, the homeless and those in extreme poverty (Biehl 2005). Vita is "the end station on the road of poverty; it is the place where living beings go when they are no longer considered people" (Ibid.: 2). State institutions, society and family abdicate

life"; a biological life stripped of value and without recourse to political recognition. Without the security of British citizenship, some women are subjected to a political system that denies them food, shelter, safety and sometimes healthcare. In this creation of "bare lives", a series of structurally violent acts are enacted that serve as possibly the biggest barrier to some African women taking ART.

5.7 Conclusions

In this chapter I have used a combination of national surveillance and ethnographic data to explore the use of ART by migrant African women in the UK during pregnancy. The findings in this thesis are largely reassuring. The majority of women take ART during pregnancy, with 80% achieving virological suppression by delivery and very few cases of vertical transmission each year. Women are committed to taking ART during pregnancy, using it as an important tool in the generation of a positive maternal and female identity. Furthermore, ART's position within a transnational *healthscape* where biomedicine is popular and widely accessed means that it is not an alien technological innovation within African diasporic settings. Women's confidence in taking ART is further bolstered by their interactions with the HIV antenatal team who deploy "the logics of care" (Mol 2008).

However, taking ART entails struggle for some women, requiring *antiretroviral work* to overcome fears about side effects, toxicity and efficacy. Women from Western Africa appear to be at greater risk of not taking ART during pregnancy than other regional groups which may be a product of high levels of HIV-related stigma that operate within many African communities, but most notably those from Western Africa.

The most vulnerable group in terms of taking ART are women who have arrived in the UK during pregnancy (many of them who are likely to have insecure immigration status). They were at greatest risk of not taking ART, not achieving virological suppression by delivery and transmitting HIV to their infants, although again the vast majority of women in this group had good clinical outcomes. Without UK citizenship, some of these women are exposed to multiple structurally violent acts, rendering their lives "bare", marked by indigence, fear and lack of political recognition. Through the resulting disparity in their capacity to take ART, an important minority of African women living with HIV (and their unborn infants) come to embody structural violence.

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responsibility for those placed in Vita, who are stripped of personhood and thereby subjected to extreme physical and psychological neglect and trauma.

Key points

- Between 2000 and 2010 over 95% of pregnant women in the UK diagnosed with HIV received ART; 80% achieved virological suppression by delivery and the rate of vertical transmission was approximately 1%.

- The use of ART was, in part, facilitated by women’s strong desire to take ART to achieve culturally sanctioned roles as mothers and good relationships with HIV antenatal specialist teams characterised by "care".

- Women from Western Africa were more likely than other regional groups not to receive ART during pregnancy, although the proportion remained small (3.6%). This may be partly due to high levels of HIV-related stigma within Western African communities.

- Women who had arrived in the UK during their pregnancy (who were also likely to have had insecure immigration status) were the most vulnerable group in terms of use of ART. For some of these women, lack of UK citizenship may manifest as extreme social and economic marginalisation, impacting adversely on their use of ART.

6

Pentecostalism and divine healing among African migrants living in London

Summary

Religion, especially Pentecostal Christianity, was described by many women during interviews as an important resource in managing HIV, whilst at the same time being cited by professionals as a potential barrier to engagement with HIV care. In this qualitative chapter I draw upon data from ethnographic fieldwork in a diasporic Nigerian church in London and interviews with pregnant women living with HIV attending NHS clinics to explore the role of Pentecostalism in managing illness, placing it in a broader cosmological framework of spiritual misfortune. I explore how these beliefs function to mediate suffering and examine the factors that underpin the popularity of new Pentecostal movements among migrant African communities in London. I then describe the nature of Pentecostal beliefs surrounding illness, with specific reference to HIV, before considering whether they act as barrier to engagement with HIV services and interventions.

6.1 Introduction

At the edges of the city, in a sprawling industrial state just off the dual carriageway, stood a non-descript red-bricked building with a tall corrugated iron roof. The building itself looked run-down, with flaking paint and woodwork discoloured by mould. The dilapidation was offset by large gold lettering spelling "T.C.P.M" on the front of the building. To the side of this hung a banner inviting people to "Experience the greatness of God's power".

Within half an hour a stream of people began to file into the back of the building. A man behind me tapped me on the shoulder, asking me how I was and explaining that this was his first time here. "Me too", I said, as he turned to greet a friend. He explained that he used to go to a different church but that he had heard that this place was different. This church was "bringing miracles". "Yes", said his friend, "This is *where to be".*

(Entry from my field diary, 27 July 2011: 3)

In Chapter Five I explored the use of ART during pregnancy by African women living with HIV in the UK. This mixed methods analysis demonstrated high uptake of ART, a good rate of virological suppression and very few cases of vertical transmission, mainly facilitated by good relationships with staff and women's desire to safeguard the health of their babies. Looking at differences *between* groups of African women, analysis of NSHPC data revealed that women from Western Africa were less likely to receive ART in pregnancy, although absolute numbers were very small. My own clinical experience, coupled with discussions with colleagues over several years, had suggested that Western African women were a particularly difficult group of patients to engage with HIV services and interventions such as ART. In the previous chapter I discussed the role of high levels of HIV-related stigma within Western African communities as a barrier to the use of ART. Another barrier commonly cited by healthcare and charity professionals during my fieldwork and my clinical work was the perceived widespread belief in divine healing. This was closely identified with African diasporic Pentecostal churches and seen as most pronounced among patients from West Africa. Initial findings from a study recently undertaken by the African Health Policy network[190] have highlighted the prevalence of claims of "faith healing" in some churches across the UK (Stevenson et al. 2013). This has been set against a background of growing media interest in divine healing and HIV. During my fieldwork two national news channels reported cases of HIV-related deaths attributed to advice from pastors at a London-based Pentecostal ministry who were alleged to have made claims about curing HIV through prayer alone[191]. Furthermore, concerns have been raised about broadcasts by "miraculous signs and wonders ministries" on religious satellite channels in which people are claimed to have been "healed" of cancer and HIV. This has resulted in the broadcast regulator Ofcom subjecting some television channels to disciplinary

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[190] The African Health Policy Network is a UK-based policy organisation addressing the health and well-being needs of Africans in the UK.

[191] See reports by BBC News London on alleged deaths attributed to the practice of faith healing at the Synagogue, Church of All Nation (SCOAN) by BBC News London on 18 October 2011 http://www.bbc.co.uk/news/uk-england-london-14406818 (accessed 23 September 2013) and Sky News on 26 November 2011 http://news.sky.com/story/903211/faith-healing-and-hiv-shatilas-story (accessed 23 September 2013). As recently as 16 August 2013, BBC News UK were reporting incidences in the UK of young people living with HIV in London and breastfeeding HIV-positive mothers who were declining ART in favour of faith healing http://www.bbc.co.uk/news/uk-23729684 (accessed 23 September 2013). Similar media interest has been shown by the media in the United States with a recently published article on Pentecostal and faith healing in the context of HIV leading to cessation of ART (Lahey 2013).

proceedings and a directive that all future claims about divine healing are accompanied by encouragement to seek medical advice[192].

Previous studies in London have shown that Africans living with HIV are largely religious (Ridge et al. 2008, Fakoya et al. 2012), the majority from non-Catholic Christian denominations with almost one in three people stating a belief that faith alone could "cure" HIV (Fakoya et al. 2012). Twenty-two of the twenty-four women I interviewed during my study described themselves as religious, mainly Christian (twenty); of whom ten were Pentecostal. Many women described the importance of their faith in managing life with HIV and references to "miraculous cures" were common. Some commented on the particular importance of Pentecostal faith in Western Africa, with one Nigerian woman remarking that Nigerians were very "superstitious" and "put all their hopes in God" to "heal them". Most work to date has demonstrated that religion plays an important role in the lives of those living with HIV[193], serving as a coping resource rather than a barrier to engagement with services[194]. However, there is evidence that that the role religion in the lives of Africans living with HIV in the UK is complex and contradictory with moralising discourse about HIV in church settings sometimes leading to discrimination and internalised feelings of shame (Chinouya et al. 2005, Doyal et al. 2005).

Bar some notable exceptions (van Dijk 1997, Hunt et al. 2001, Hunt 2002, Adogame 2004, Harris 2006), Pentecostalism in African migrant populations in resource-rich countries remains a relatively overlooked area of study. Work in this area has tended to focus on material culture such as the use of anointing oils (Botticello 2009), ritual and belief (Adogame 2004, Harris 2006), or the role of churches in forging diasporic identities (Hunt 2001, van Dijk 1997). The construction of health and illness within Pentecostal cultures has not been explored in great detail. Adogame (2007) remains the only scholar to have explored the role of African Pentecostal churches in confronting HIV, although this ethnographic research was conducted mainly within Nigeria rather

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[192] See the press statement by a church organisation that attended this meeting, which highlights the tensions between the right to religious expression and the need to meet UK broadcasting standard http://www.cte.org.uk/Articles/353604/Churches_Together_in/News_Events/News/Black_Church_leaders.aspx (accessed 16 September 2013).

[193] Religion has been shown to improve wellbeing in those living with HIV (Ridge, et al. 2008) and reduced levels of depression and anxiety (Polzer Casarez, et al. 2008, Braxton, et al. 2007).

[194] Quantitative work conducted in London have not demonstrated an association between religiousness, and uptake of or adherence to ART (Tariq, et al. 2010, Fakoya, et al. 2012).

than focusing on the diaspora itself[195].

In summary there is a dearth of work exploring the day-to-day lives of migrant Africans living with HIV, especially within a UK setting, despite growing concerns amongst healthcare and charity professionals about the impact of divine healing on engagement with HIV care especially among Western Africans. Media representations of divine healing in the context of HIV in the UK have tended to portray churches as exploitative and believers as irrational, conforming to a wider pattern of "media sensationalisation" that trades on "exoticised images of African and African-derived religions" (Adogame 2004: 515). Influenced by the work of Dan Sperber, I seek to engage with these "apparently irrational beliefs" (1985: 37)[196].

In this chapter I present the first study within the UK to specifically explore the role of Pentecostal faith in the lives of migrant Africans living with HIV. I wish to challenge dominant stereotypes about churches such as TCPM within healthcare settings and the mainstream British media, highlighting both the benefits and challenges it presents to those living with HIV and those involved in their care. I draw primarily upon material gathered during six weeks of fieldwork between July and September 2011 at the Triumph of Christ Pentecostal Ministry (TCPM)[197], a Nigerian Pentecostal church on the outskirts of London, during which I regularly attended church services and extended prayer vigils. My analysis is supplemented by data from in-depth interviews with two members of TCPM's congregation and a content analysis of literature published by the church. I also refer to findings from my qualitative interviews with pregnant African women living with HIV attending NHS clinics.

Firstly I describe Pentecostal cosmology as exemplified by the TCPM in order to situate beliefs about illness (including HIV) within a broader cosmological framework that

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[195] In his work on the Redeemed Christian Church of God (RCCG), one of the most successfully globalised Pentecostal churches in the world, Adogame explores how misfortune is addressed through the notion of spiritual warfare in which adherents are implored to counter demonic attacks on a wide variety of ills such as sickness, (including HIV), poverty and infertility through a rich constellation of religious practices. Although, Adogame recognises the challenges presented by the RCCG's claims to cure those living with HIV, he is careful to emphasise how the narrative of healing engenders hope and allows people to cope with a highly stigmatised condition, thereby performing " important religious, social and therapeutic […] functions" (Adogame 2007: 482).

[196] An invitation to slay a dragon during his own fieldwork in Ethiopia prompts Sperber to explore "apparently irrational beliefs". He rejects intellectualist approaches that view irrational beliefs as mistaken and resulting from a lack of information or understanding, and symbolist approaches that posit a non-literal meaning. Importantly, Sperber also critiques the classical anthropological position of cognitive relativism in which all beliefs are valid in their own cultural context, arguing that it has little theoretical and empirical basis in cognitive psychology. Instead he explores the cognitive role of this form of thinking in processing abstract open-ended concepts.

[197] Throughout this thesis I use a pseudonym to protect the identity of this church.

addresses misfortune. I then discuss the factors that underpin the popularity of new Pentecostal movements among migrant African groups in London and explore how Pentecostal beliefs function to mediate suffering. The exploration of both broader Pentecostal cosmology and factors in Pentecostalism's widespread appeal among African migrants is critical to understanding the role of Pentecostalism in the lives of people living with HIV and challenging any preconceptions of their irrationality. I conclude by considering whether Pentecostal beliefs serve as a barrier to engagement with HIV services and interventions.

6.2 Overview of Pentecostalism

In a review of the globalisation of Pentecostal Christianity, the anthropologist Joel Robbins writes that "there is little standardization in social scientific usages of terms such as Pentecostal and charismatic" (Robbins 2004: 119). The taxonomy of this variant of Christianity is complex and shifting, and many terms used by scholars also have widespread lay usage that are specific to local contexts (Robbins 2004, Anderson 2010). However, it is possible to identify certain core features shared by many of these churches, allowing us to use the term "Pentecostalism" heuristically whilst recognising the diversity of churches that it may encompass (Robbins 2004, Anderson 2010). In this chapter, I use Pentecostalism to refer to the form of Christianity in which believers emphasise a direct personal experience of God, founded upon baptism in the Holy Spirit by which spiritual gifts (*charisms*), such as speaking in tongues (*glossolalia*), healing and prophesising are bestowed upon adherents[198]. It is this "shared emphasis on ecstatic experiences that are available to all believers" that Robbins states characterises Pentecostalism (2004: 122).

The roots of contemporary Pentecostalism lie in eighteenth century Protestant Evangelism in the UK and North America and its emphasis on religious conversion and a highly emotionally-charged style of preaching (Kay 2011), although it is the Charismatic revivals in the early twentieth century that are the main antecedents of

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[198] It is beyond the scope of this chapter to review the theological underpinning of Pentecostalism. The term is derived from the Day of the Pentecost and it is founded upon a literal interpretation of the Bible with particular emphasis on the Acts of the Apostles in the New Testament and passages describing the supernatural manifestations of the Holy Spirit (Kay 2011). These passages describe collective experiences of the Holy Spirit which are egalitarian and available to all culminating in glossolalia,, a powerful demonstration of the Holy Spirit's overwhelming capacity to empower believers to achieve things that they could not previously do. Other key passages in the New Testament relate to divine healing, prophecy and the importance of proselytising.

contemporary Pentecostalism[199]. Pentecostalism (and similar Charismatic Christian movements), with its focus on missionary work and emphasis on spiritual power, was particularly successful during colonial expansion in Africa in the nineteenth century, leading to the establishment of many African churches of this tradition. Pentecostalism's engagement with a spiritual realm, divine healing and relative lack of formal liturgy were consonant with many pre-existing African religious modes of worship (Anderson 2001, Harris 2006, Kay 2011). At the turn of the twentieth century, nascent desires for self-expression amongst many Africans led to a breakaway from traditional European missionary churches and the formation of African Independent Churches (AICs) with African leadership and the incorporation of older African religious elements to a greater or lesser extent (Anderson 2001)[200].

Since the 1970s a new type of Pentecostalism has gained popularity in Africa, especially Western Africa[201]. These new churches deliberately set themselves apart from AICs, instead taking their inspiration from Euro-American Pentecostal leaders and their liturgical style (Meyer 1998b). These churches predominantly appeal to a young and aspirational burgeoning African middle class and promulgate individualism, professionalism and an intertwining of spiritual and economic success, together known as the "Prosperity Gospel" (van Dijk 1997). Often headed up by intensely charismatic leaders with flamboyant displays of wealth, material success is perceived as a manifestation of God's power and favour. These new Pentecostal churches, many originating in Africa with headquarters based in enormous megachurches[202], have a

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[199] In the late 19th century, the Holiness movement within Methodism began to develop a form of religious practice that emphasised the supernatural and experiential aspects of Christianity, in particular faith healing and speaking in tongues. At the turn of the twentieth century, a series of seemingly unconnected religious *revivals* appeared to spring up around the world. One of the most important was the Asuza Street revival (1906-1909) led by William Seymour, an African-American son of slaves. From the outset, the Asuza Street revival was noted for its racial, gender and social class mixing. It was characterised by intensely enthusiastic worship, accompanied by singing, clapping and public testimonies which themselves are likely to have had roots in African-American slave religions. This style of worship and the emphasis on religious phenomena such as glossolalia and divine healing has been a major influence on contemporary Pentecostalism. It also influenced more historically mainstream Christian denominations, leading to the development of Charismatic Movements within Catholicism and Anglicanism in the 1960s (Robbins 2004, Kay 2011).

[200] Many of these churches such as *Spirit Churches* in Ghana and *Aladura* in Nigeria emphasise spiritual power and manifestations of the Holy Spirit. See Meyer (2004) for a detailed overview of the history of Pentecostal movements in African and the transition from AICs to contemporary Pentecostalism.

[201] Hunt and Lightly, in their ethnography of an RCCG church in West London, describe the broader social and economic conditions that favoured the rapid growth of modern Pentecostal churches in Nigeria. Churches espousing material success, individualism and hard work flourished in the 1980s following widespread state corruption, the collapse of Nigeria's oil economy and the subsequent state Structural Adjustment Programme which resulted in severe economic hardship throughout the country (2001).

[202] Such as the Redeemed Christian Church of God's *Redemption Camp* in Lagos (see http://rccg.org/index.php/about-us-2/history/, accessed 14 August 2013) and the Winners' Chapel's *Faith*

strongly international outlook (van Dijk 1997, Coleman 2000) seeing the global stage as an opportunity to evangelise and successfully establishing ministries all over the world. The rapid growth of this new form of African Pentecostalism in the past forty years has been fuelled by neoliberalism, technological innovation, mass-media and the widespread globalised social imaginary (Meyer 2010)[203]. Furthermore, Pentecostalism's relative lack of fixed doctrine, its egalitarianism and its operation outside of a centralised religious structure, gives it an inherent flexibility to adapt to local contexts whilst maintaining a global identity.

In 2005 it was estimated that there were just under one million Pentecostal Christians in the UK attending approximately 2200 Pentecostal churches with increasing attendances especially by people from minority ethnic groups[204] (Evangelical Alliance UK 2008). It is hard to know with accuracy how many Pentecostal churches of African origin exist in London in 2013. The Redeemed Christian Church of God (RCCG) has over 100 branches in London alone[205]. What is certain is that the Pentecostal landscape in London is composed of a rapidly evolving constellation of churches from different traditions, albeit sharing some of the core Charismatic features described earlier, ranging from older Charismatic and AICs to the newer Pentecostal churches either founded in Africa or in the UK and attracting mainly African adherents.

6.3 The Triumph of Christ Pentecostal Ministry

6.3.1 Overview of the Triumph of Christ Pentecostal Ministry

The Triumph of Christ Pentecostal Ministry (TCPM) was founded in 2005 and is a relatively new church compared to more established and well known ministries in the UK such as the RCCG and the Winner's Chapel, both of which were founded in Nigeria before establishing branches internationally. In contrast the TCPM, like the London-based Kingsway International Christian Centre (KICC) before it[206], was founded in

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Tabernacle in Ogun State also in Western Nigeria (see http://domi.org.ng/aboutus/timeline, accessed 14 August 2013), both of which are able to accommodate over 100,000 worshippers.

[203] The notion of the *social imaginary* was developed by Charles Taylor who describes it as "the way ordinary people "imagine" their social surroundings. […] it is often carried in images, stories, and legends […] the social imaginary is the common understanding that makes possible common practices and a widely shared sense of legitimacy" (2002: 106).

[204] Information obtained from English Church Census 2005 available at http://www.eauk.org/church/research-and-statistics/english-church-census.cfm, accessed 26 September 2013.

[205] See the RCCG website for further details of the church at www.rccg.org.

[206] See the KICC website for further information on the church at http://www.kicc.org.uk.

London, primarily attracting adherents from the West African diaspora[207]. The TCPM belongs to the new movement of Pentecostal churches as outlined earlier. It has few ties to older, more Africanist churches, instead borrowing its style heavily from contemporary American evangelical Christianity. It has an explicitly international orientation, reflected by its satellite broadcasting of church services and organisation of international conferences, and a focus on the Prosperity Gospel espousing material, physical and spiritual success. Furthermore it presents itself as a place of contemporary worship, adopting digital technology such as downloadable church literature for e-readers and apps for smart phones, thus appealing to a young, mobile and aspirational audience.

The TCPM, like other similar churches, was founded outside a traditional ecclesiastical structure by one man, Pastor Emmanuel[208]. The story of Pastor Emmanuel's conversion to Pentecostalism and the subsequent creation of the ministry is a core part of TCPM's identity, with fragments of the story recounted in church literature, on its website and during sermons. His conversion narrative follows a conventional format found within Pentecostalism as described by Coleman in his study of Swedish Pentecostals (2000). Interestingly, it most closely resembles that of David Oyedepo, the founder of the Winner's Chapel who is widely regarded as one of the most successful Pentecostal pastors in Nigeria with a huge international ministry and an estimated net worth of $150 million (Nsehe 2011)[209]. Pastor Emmanuel's conversion narrative involves a failed migration project resulting in financial loss and family dishonour on his return to Nigeria, followed by a "vision" from the Holy Spirit prophesising the creation of a new ministry in London. This was accompanied by other "spiritual gifts" including the power to heal[210], leading ultimately to great success in the form of marriage, children and the founding of his own ministry. The Pastor's conversion narrative highlights key preoccupations within the congregation of TCPM in London: failed migration projects (van Dijk 1997); the struggle for material wealth; healing from sickness; and marriage and reproduction. Furthermore, it encapsulates Pentecostal cosmology, foregrounding

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[207] The predominance of African adherents within these churches is well-recognised. For instance, Hunt describes the ethnic composition of the RCCG church in which he conducted fieldwork as 96% "African", with 90% describing themselves as "Nigerian" (Hunt et al. 2001).

[208] All names are pseudonymised.

[209] Oyedepo founded his ministry in 1981when suffering similar economic misfortune and describes conversion after receiving "visions" from the Holy Spirit imploring him to "liberate the world from all oppression of the devil through the preaching of faith". Spiritual discourse and preaching style within the TCPM echoes that of Oyedepo's. See http://www.davidoyedepoministries.org (accessed 23 February 2013).

[210] In his biography in church literature, Pastor Emmanuel makes specific reference to an occasion when he "resurrected" a man who had died of an HIV-related illness.

the power of the Holy Spirit to bestow supernatural gifts such as visions and healing.

Since its foundation in 2005 the TCPM has grown into a national ministry with four branches throughout the UK including two in London, and claims on its website to be one of the fastest growing churches in Europe. It has a successful business portfolio comprising shops, religious conference organisation, and most importantly a media empire that includes print publication of church literature, television and radio studios, and a satellite television channel hosting broadcasts from other ministries internationally. These businesses provide an important stream of income supplementing *tithes*, financial contributions from the congregation that are viewed as a Biblical requirement[211]. The TCPM's broadcast media arm allows it to position itself successfully within the global *mediascape* (Appadurai 1996). It is able to extend its evangelising beyond the confines of its churches and transcend national boundaries, allowing it to pursue its mission of becoming an international ministry. The broadcasting of church services has been a successful strategy in that many members of TCPM's congregation were drawn to the church from a wide area in South East England, often at the expense of other churches, after watching broadcasts of healing services that established its reputation as a place where "miracles happen"[212].

6.3.2 The Triumph of Christ Pentecostal Ministry, Greater London

The work I present in this chapter is based on fieldwork conducted in the TCPM's oldest and largest congregation attracting up to four hundred members to weekday services and over a thousand at weekends and twice-monthly night vigils. The congregation is based in TCPM's main headquarters occupying several sites on an industrial estate on the outskirts of London. The TCPM occupies several buildings in the area, two of which are used for church services. Both church spaces were formerly secular spaces that have been sacralised by the church; one a former sports hall in which daily services are held, and the other a large office block that is the site of the hugely popular Sunday services and all night vigil[213] . Neither of the TCPM's church spaces were purpose-built for religious use, and both eschew the ornamentation that is

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[211] This model of expansion, although unusual within more established denominations of Christianity, is not unusual within the new wave of Pentecostalism, and echoes that of Sweden's *Word of Life* church (Coleman 2000).

[212] This is in contrast to membership of the RCCG, which is often forged through existing networks of family, friends and acquaintances (Hunt 2002).

[213] The sacralisation of urban space is not uncommon within the new wave of Pentecostalism and is sometimes met with hostility such as the local protests launched in South London against the KICC's purchase of a former bingo hall for religious use (Lidbetter 2009).

commonly found in churches of other Christian denominations (figure 6.1). The church interiors are large, sparsely furnished and functional spaces, able to accommodate hundreds and even thousands of attendees (figure 6.2). The focal point is the stage on which services are delivered, which are surrounded by broadcast technology including camera rigs, large plasma-screens, speakers and microphones, a reminder of the vital role played by broadcast media in the constitution of new Pentecostal churches' identity and mode of worship (Coleman 2000, Meyer 2006).

The church operates one-to-one counselling with the Pastor, a Bible study group, a women's group, a men's group, a group for single people, a children's group and a welfare department designed to provide practical support to those requiring financial or legal assistance. However, its focal point is the daily *deliverance* services that last up to four hours, with longer services on weekends and fortnightly night vigils. Most church services are conducted by Pastor Emmanuel who is described in the church's literature as "endowed by God with an unusual anointing for healing, miracles, extraordinary breakthroughs and deliverance"[214]. Services follow a predictable format, typical of many churches of this kind, with prayers (often in tongues), followed by gospel songs by the church choir and then a sermon by Pastor Emmanuel that often focuses upon "miracles, signs and wonders". The services conclude with an invitation to members of the congregation to come forward for anointing with blessed oil or healing by the Pastor.

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[214] A direct quote from the Pastor's biography that is printed on the cover of TCPM magazines.

Figure 6.1: The Triumph of Christ Pentecostal Ministry Greater London, small church hall*

Figure 6.2: The Triumph of Christ Pentecostal Ministry Greater London, interior of small church hall*

*All photographs taken by Shema Tariq, September 2011

6.4 Cosmology of the Triumph of Christ Pentecostal Ministry

6.4.1 Spiritual realm

The world as conceived by TCPM, like other Pentecostal churches, is populated by a panoply of unseen spiritual forces (Meyer 1998a, Adogame 2004, Harris 2006):

> "It is impossible for us to see spirit beings. They are like the wind; present but cannot be seen. We only feel the wind and destruction it causes […] why am I talking about satanic beings? Firstly because they are the ones that are responsible for our captivity and secondly because we need to subdue them in order for us to be delivered."
>
> (Extract from TCPM publication on deliverance, 2009)

The Pentecostal spiritual realm differs from that of other Christian denominations in its emphasis on carefully elaborated demonic forces as well as the more familiar divine entities such as God, Jesus and the Holy Spirit. This explicit acknowledgement and engagement with the spiritual realm has been described as consonant with indigenous beliefs in a variety of settings in African and the diaspora[215] and is an important factor in the success of many Pentecostal and Charismatic churches. For instance, Engelke describes the widespread beliefs in evil spirits and use of *n'angas* (traditional healers) by *we*Chishnu Masowe Apostolics[216] in Zimbabwe. As a result, local churches that reflect the reality of evil spirits are viewed more favourably than mission churches, which often deny their existence:

> "The problem with foreign churches – by which the *we*Chishnu mean mission churches which have refused to recognize African culture – is that they deny the existence of spirit mediums, witches, avenging spirits and the like […] Foreign churches cannot address the spiritual problems of Africans because they deny the roots of such problems."
>
> (Engelke 2004: 93)

The TCPM typifies Pentecostal churches in its construction of a universe populated by

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[215] Harris in her ethnography of a Yoruba Aladura church discusses the overlap between Yoruba notions of spiritual power and interlinked spirit and material worlds (2006). Both Engleke in his work with Apostolics in Zimbabwe (2004) and Meyer in her work with Ghanaian Pentecostalists (1998) highlight the importance of the recognition by churches of indigenous belief systems that centre on evil spirits.

[216] The Apostolic church is a prominent Pentecostal church in South Africa, Zimbabwe and parts of Central Africa.

the divine forces of God and malevolent spiritual agents, which are recast as agents of the Devil. This construction of a dual cosmological space comprising interpenetrating spiritual and material worlds (Adogame 2004) allows for the possibility that ritual action appealing to forces within the spiritual realm will enact transformation in the material world:

“By the authority of Jesus Christ you can end your troubles. All it will take is your faith and your tongue. Stand up and charged with faith, command the thorns in your flesh to burn to ashes […] You will be amazed how easily these thorns will listen to your voice of faith.”

(extract from TCPM publication on deliverance, 2009)

However, the relationship between the TCPM and indigenous belief systems is complex. It cautions against “being enticed by evil powers” in seeking solutions from “palmistry, astrology and sorcery”[217], warning that “if you ever gain from evil powers, you become an evil person yourself”. On the other hand, traditional preoccupations of diviners and healers such as curses brought on by kin[218], have been appropriated, diabolised and subjected to the power of God:

“In the name of Jesus, I command you

Every chain will be broken,

In the name of Jesus

Every curse from my family, from my wife, from my village, from my farm,

I renounce you.

Family curses, parental curses, ancestral curses, generational curses, spiritual curses,

I destroy you in the name of Jesus.”

(Extract of TCPM prayer, 30 August 2011)

In this TCPM prayer, curses that would be familiar to many in TCPM’s congregation are reframed as the work of Satan, with the past acknowledged as having the power to

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[217] See also Meyer (1998) on Ghanaian Pentecostal churches’ demonisation of traditional religions, which are accused of occult practices.

[218] See Auslander on Ngoni witchfinding in Zambia where mothers and grandmothers were accused of destroying both biological and socioeconomic reproduction (1993). Also see Whyte’s accounts of divination in Eastern Uganda, which predominantly focus upon relatives as agents of misfortune (1997).

create disturbance in the present[219].

The spiritual world therefore has a tangible presence within the lives of those at TCPM. Demonic forces are believed to be "universal beings; they are not restricted to a particular place on the face of the earth" (extract from TCPM publication on deliverance, 2009). They have "a mandate to perpetuate evil" (ibid.) and are seen as the cause of all personal misfortune:

> "The children you never had, the husband that proved elusive all through your fruitful years, the promotion that never came, the job and education that never came, the house that was repossessed, the salary that was denied you etc. could have been stolen and kept from you by the devil."
>
> (Extract from TCPM publication on deliverance, 2009) [220]

The reach of these demonic forces extends far beyond the private sphere with Pastors at the TCPM accusing the Devil of being the "puppet-master" behind youth knife crime in London and on the global stage of being the cause of a reported ambush on American troops in Afghanistan by the Taliban, describing their subsequent escape as a "miracle" of God. The Pentecostal world is therefore a polarised one, set up as a battle between good and evil spiritual forces on a global scale. Similarly to rhetoric described within the RCCG (Hunt 2001, Adogame 2007)[221], motifs of warfare abound within the TCPM. Militarised language is a core feature of services as the congregation are urged to "enter into spiritual warfare" with "spiritual invisible bullets" using "power", "force" and "the word of God as a sword to fight demons and make them bleed in the spiritual realm", with explicit parallels drawn between this spiritual war and the physical battlegrounds in contemporary conflicts (extract from TCPM publication on deliverance, 2009). This is a totalising system of meaning in which all misfortune is ascribed to supernatural causes, and where good fortune is especially vulnerable to attack. The onus is on each member of TCPM to use the Lord as a "shield" to protect themselves from evil spirits, and to engage in a range of rituals in order to "keep their miracle", whether that be

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[219] Meyer discusses Pentecostal attitudes towards the "past" in her work on Ghanaian Pentecostalists (1998). Deliverance is preoccupied with securing freedom from the influence of both the immediate past and an individual's "sins", and their "ancestral past" through which they are punished for sins committed by previous generations.

[220] The prominence of concerns regarding marriage, fertility and career success have been described among Pentecostals in London (Hunt 2002) and Zimbabwe (Engelke 2004).

[221] The idiom of spiritual warfare is common across Pentecostalism. See Csordas' description of deliverance rituals within Charismatic Renewal Movement in the United States (1997).

health, employment, marriage, fertility or immigration papers[222].

6.4.2 Deliverance

A key ritual practice through which spiritual warfare is enacted is *deliverance*, which is described as:

> "…freedom or liberty or redemption […] When it is said that somebody needs 'deliverance', it means by implication that the person in question is not free. He or she may be in bondage or in captivity against his or her wish. It implies also that captives or victims of bondage are not able to free themselves from the grip of their captors, even though they may be desperately willing to be set free."
>
> (extract from TCPM publication on deliverance, 2009)

Church services are filled with references to bondage and the severing of ties, with the congregation regularly asked to physically enact the "chopping" of the spiritual chains that bind them. Deliverance occurs spontaneously within church services or through the laying on of hands by the Pastors, and through one-to-one counselling sessions with Pastors. It also requires commitment outside the confines of the church with fasting and intense prayer "delivering" individuals from the influence of "satanic beings" that are responsible for this "captivity". Through these ritual acts individuals can achieve deliverance, thereby freeing themselves from the malevolent influence of the Devil on their lives in order to "possess [their] miracle". However, deliverance is not an isolated event in an adherent's religious life. Rather, it is an enduring practice in which people actively participate to secure their freedom amidst the constant threat of evil spirits, recalling Csordas' notion of "incremental efficacy" (Csordas 1997: 72)[223]. The world as constructed by TCPM, as is the case in other Pentecostal churches, is inherently threatening, populated by unseen "enemies" who will continually try and "steal" your destiny (extract from TCPM publication on deliverance, 2009). Safeguarding deliverance therefore places great demands on adherents, requiring lengthy attendances at church services several times a week and incurring significant financial costs in the form of regular tithes, travel costs and the repeated purchase of religious material such

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[222] These were the most commonly cited issues in TCPM services, literature and promotional material.

[223] Csordas describes ritual healing among adherents to the Charismatic Renewal Movement in the US as unfolding over time. He states that "miracles of spontaneous and total healing" are rare and that healing mainly occurs through consistent engagement with the healing process, including in daily practice outside the confines of formalised ritual. For Csordas, this is a product of Charismatic healing's mode of action which is to transform the self, a process that is fundamentally indeterminate and open-ended (1997: 72).

as church publications and ritual objects[224].

6.4.3 Power of the Word

A central component of deliverance and religious practice more broadly at TCPM is the Word of God[225]. The Word of God is central in TCPM church services. The sparsely decorated church interior (figure 6.2) reflects the rejection of external stimuli in favour of the development of a close personal relationship with God through words in the form of intense prayer. As described earlier, the most prominent feature in the church halls is the array of broadcast technology, designed to amplify and transmit God's Word to the congregation and beyond. Biblical readings, highly charismatic preaching and "testimonies" (personal accounts of deliverance relayed by members to the congregation) dominate church services and are used to effect transformation in people's lives. This is exemplified by the range of "Action Prayers" at the TCPM which are thought to be especially "powerful prayer points" to be used to secure success:

"With my tongue, I clear every obstacle on my way in Jesus name.

With my tongue, I clear every barrier against my increase in Jesus name.

My tongue is anointed to rule therefore I say that I rule over my enemies in the mighty name of Jesus Christ."

(Extract from TCPM publication on the power of words, 2009)

An important manifestation of God's Word within the TCPM is *glossolalia* (speaking in tongues). It is a core feature of Charismatic and Pentecostal churches and is defined by Virginia Hine in her seminal paper on glossolalia as "a form of unintelligible vocalization which has non-semantic meaning to the speaker, and is interpreted in the Bible as a divinely inspired spiritual gift" (1969: 211)[226]. Initially appearing chaotic

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[224] For example at TCPM commonly used objects were prayer cloths, blessed oil and blessed cordial.

[225] Csordas also highlights the importance of ritual language in the Charismatic Renewal (prophecy, prayer, teaching and through sharing of religious experience) which are a "rhetorical means of ordering experience and directing attention" and words with highly specific religious meaning which "play a role in orientational self-processes [anticipating] the situational consequences of participants'' actions and [implying] strategies for action" (1997: 22). Engelke's work with the *we*Chishnu Masowe Apostolics in Zimbabwe also identifies the central role of the spoken word in forging a connection to God. However it is a church that prides itself, in its own words, as being "the Christians who don't read the Bible", instead drawing upon performative religious language which "collapses the distance between God and the congregation in both spatial and temporal terms" (Engelke 2004: 87).

[226] "But the manifestation of the Spirit is given to every man to profit withal. For to one is given the Spirit the word of wisdom; to another the word of knowledge by the same Spirit; to another faith by the same Spirit; to another the gifts of healing by the same Spirit; to another the working of miracles; to

and disorientating, there was an underlying discipline and patterning of vocalisations in individuals at the TCPM despite its apparent "urgency and spontaneity" (Coleman 2000: 134)[227]. Members were primed during services to expect to receive the gift of tongues from the Holy Spirit and were surrounded by others speaking in tongues, thus shaping a charismatic habitus. Furthermore, it was expected to be performed within set parameters and at defined points of the service[228]. Glossolalia serves a range of purposes for members of TCPM. It is a marker of baptism within the Holy Spirit, it facilitates a close personal relationship with God, it is a direct channel for prayer and it can be a source of comfort and joy[229]:

it [speaking in tongues] began another open door of my spiritual world with God [...] I mean you feel good [...] praying in English is using your mind to pray but praying in tongues it's just kind of coming from within you.

(Sarah, member of TCPM congregation)

Sarah (above) described speaking in tongues as part of her day-to-day life rather than a ritual practice reserved for church, often using it to facilitate a fast connection with God. Far from being an esoteric ritual practice, glossolalia is therefore embedded within people's quotidian lives, enabling immediate access to spiritual power outside of church and providing a rich and portable source of religious self-efficacy.

6.4.4 Spiritual power

Harris, in her study of a Yoruba Aladura church in London, highlights spiritual power as the "central organising principle" within Pentecostalism (2006: 58). The world of the TCPM is suffused with spiritual power. Religious discourse is filled with references to "fire", "prayer bombs" and "breakthroughs" with prayer, fasting and speaking in

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another prophecy; to another discerning of spirits; to another diverse kinds of tongues; to another the interpretation of tongues." (Corinthians 12: 7-10, *Holy Bible: King James Version*).

[227] In contrast to previous notions of glossolalia as a process available to anyone willing to "adopt a passive attitude about controlling speech" (Mansell Pattison cited in Hine, 1969: 220), Csordas also views it as an active process which initially involves intentional active utterance of "whatever nonsense syllables she [adherent] can formulate" (Csordas, 1994: 273). Both Csordas (1994) and Coleman (2000) highlight the role of past experience and a specific religious predisposition in the manifestation of the phenomenon.

[228] Those who fail to perform by speaking in tongues at an inappropriate point in the service are perceived to be "drunk on the spirit" and admonished.

[229] See also Hine's observation that Pentecostals involved in the "tongue movements" described a range of positive emotions including increased capacity to love, patience and increased self-confidence (1969: 216).

tongues functioning to harness God's power in order to secure deliverance[230]. This transformative power of God's Word also extends to material objects as TCPM members draw upon a range of ritual blessed objects blessed by the Pastor including oil, water, cordial and prayer cloths[231]. These preparations and objects are then placed upon their bodies or ingested, facilitating an embodiment of the Word and God's power:

> *The oil is the symbol of the Holy Spirit – the active part of God. You can take cooking oil that you fry an egg in, you pray on it and it becomes a supernatural power. You put it on you and it becomes a symbol of the Holy Spirit in you.*
>
> (Sarah, member of TCPM congregation)

These ritual objects are used as part of deliverance to collapse the distance between God and the bodies of the congregation. They are also used widely outside of church as a way of accessing God's power in other spaces, another demonstration of the flexibility and portability of Pentecostal religious practice.

Intertwined with spiritual power within the TCPM is the notion of "fruitfulness" which refers to both material and spiritual success. The language of "fruitfulness" dominates the church's discourse with repeated references to "abundance", "supernatural harvest" and the planting of "seeds" (tithes) that will grow and deliver spiritual breakthroughs. Therefore spiritual power is channelled for a specific purpose within the TCPM; that is to bring about fruitfulness whether that be success in business, the bearing of children or immigration matters.

In summary, the cosmology of the TCPM is typical of Pentecostal churches in that it constructs a world where the spiritual and material realms interpenetrate and where individuals live in constant threat from satanic spirits. Deliverance is centred upon the power of God's Word and ritual practice, forming a rich armoury that member of the church can draw upon as they engage in ongoing spiritual warfare to free themselves from demonic forces that may be negatively impacting their lives in any sphere.

6.5 The promise of transformation

The TCPM is growing in popularity with new branches being established across the

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[230] This is perhaps best encapsulated by the church's mascot, the eagle, "a bird that can fly on extremely high places. A bird of power" (extract from monthly TCPM publication, December 2010).

[231] In her ethnography of a Nigerian Pentecostal church in London, Botticello describes how faith is reinforced by "tangible forms that materialize the intangibility of God and his Word" (2009: 82). These "tangible forms" range from food to a variety of other ritual preparations such as oil, water and soap.

country and an expansion of its congregation. This reflects a global resurgence in Pentecostalism, which is now the most rapidly growing denomination of Christianity with at least 500 million Pentecostal Christians worldwide (Pew Forum on Religion & Public Life 2006), many of whom live in resource-poor settings. This leads us to ask: what attracts adherents to Pentecostalism in the face of diminishing congregations within other Christian denominations and the perceived increasing secularisation of society?

In section 6.4.1 I touched upon the resonance of Pentecostalism with indigenous spiritual ontologies, which some authors see as central to the global success of Pentecostalism especially within Africa (Kalu 2003)[232]. However, this was not how my participants framed their decision to attend Pentecostal churches. Robbins argues that approaches emphasising "cultural continuity", risk overlooking a core aspect of Pentecostal belief and practice:

> "For when one takes seriously what Pentecostals understand themselves to be doing, one discovers that most often they are trying to change. They are involved, that is, in personal and collective projects of discontinuity framed very much in Christian terms."
>
> (Robbins 2003: 230)

Robbins identifies the notion of discontinuity, or "rupture" as an important analytic entry point in the study of global Pentecostalism (Ibid.). In her work with Ghanaian Pentecostals, Birgit Meyer describes her participants' preoccupation with making "a complete break with the past" (Meyer 1998a)[233]. However, inherent in the discourse of "separation" and "breaking bonds" within the TCPM is the quest for transformation, highlighted by its central motto: "Your story is changing". In this section, I argue that it is the notion of transformation that is key to understanding how Pentecostalism becomes "a central category of cultural practice in which lived lives embody an evolving religious understanding of the ultimate meaning of life" (Kalu 2003: 88).

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[232] Both Harris (2006) and Adogame (2004), in their work on Pentecostal practice in the African diaspora, foreground the overlap between Yoruba indigenous cosmologies and the spiritual realm constructed within Pentecostalism.

[233] For the Ewe Pentecostals in Ghana, breaking with the past involves deliverance from evil spirits, many of who originate in the past in the form of generational curses, and also severing of ties to kin in order to live as a "modern individual" without obligations to an extended clan (Meyer 1998: 336). However several authors highlight the ambiguity of rupture in Pentecostalism in that it involves remembering and taking seriously the very things Pentecostalists seek to break away from (Robbins 2003, Meyer 1998, Engelke 2004). This is encapsulated by the acknowledgement of indigenous practices such as divination but their recasting as the work of the devil and the engagement in ongoing spiritual battle against them.

In his 2004 review article on global Pentecostalism, Joel Robbins discusses the preponderance of theories of "deprivation and anomie" in sociological analyses of contemporary Pentecostalism (Robbins 2004). These theories seek to explain the attraction of Pentecostalism to socially marginalised groups, emphasising its roots in the early twentieth century as a movement attracting migrants and those from lower social classes. To those mired in poverty and other types of social suffering, Pentecostalism offers a transcendent escape, providing hope for a transformation of circumstances (Ibid.)[234]. As the TCPM states, "God invites the heavy-laden to come to Him so that he can give them rest" (Extract from TCPM publication on deliverance, 2009). In addition to spiritual salvation, the TCPM can be distinguished from non-Pentecostal churches by its explicit engagement with the day-to-day difficulties of life as a migrant African such as unemployment, poverty, poor health and relationship difficulties[235]. Its newly established social welfare department locates it firmly in the quotidian lives of its members', providing assistance in matters ranging from immigration issues to destitution to the development of business opportunities[236] in order to effect a material transformation. Furthermore it cultivates an entrepreneurial orientation as demonstrated by church literature espousing self-development and employment success, borrowing heavily from the discourse of self-help[237]. With the success of migration projects paramount to the economic survival of kin, the promise of success and prosperity is of central importance (Van Dijk 1997).

The TCPM provides a tightly knit community and a ritual practice that is highly structured and time-consuming but also enjoyable, with members describing it as "a kind of spiritual party" that is "lively" and "energetic" compared with other "sombre" and "routine" churches. It also facilitates a sense of belonging to a larger collectivity, both within London and beyond. Meyer describes Pentecostalism as a "globalising religious project" partly founded upon its imaginary of the world and its outreach and spread (Meyer 2010: 114). A defining characteristic of churches such as the TCPM is

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[234] Robbins writes "To the deprived, those who feel they are not getting their lot in life, [Pentecostalism] offers ecstatic escape, hope for millennial redress, and an egalitarian environment in which everyone is eligible for the highest religious rewards (i.e. salvation and gifts of the Spirit)" (2004: 124).

[235] This is highlighted in Van Dijk's ethnography of the Ghanaian Pentecostal diaspora in the Netherlands. He describes the role of Pentecostalism in the forging of diasporic identities through prayers to secure successful migration projects, assistance with unemployment and legal status, and the provision of a "safe, personalistic network in the host country" (1997: 15).

[236] Examples of material assistance given by the TCPM included the provision of funds to one of my participants with no recourse to public funds for the funeral of her stillborn baby, and the promotion of members' businesses through a church conference in August 2011.

[237] For instance in one "devotional guide" chapter titles include "Embrace encouragement", "Project boldly", "Plan wisely" and "Value yourself" (from TCPM "Daily Devotional Guide", August 2011).

their international orientation. TCPM's imaginary of the world extends far beyond the confines of its branches in the UK. It maintains close links with the United States through its connections with American evangelists, and with West Africa (particularly Nigeria) through the regular flow of pastors, members and money across continents. Furthermore its successful position on the global stage through its highly adept use of digital and broadcast media have allowed it to reach an audience that extends throughout the world. The TCPM is therefore not a geographically bounded community, but is instead one that inhabits a transnational *sacroscape* (Tweed 2008)[238], providing familiarity in terms of beliefs, practice, food, dress and language whilst at the same time specifically orientating itself towards the difficulties and aspirations of those in the diaspora.

As well as offering the promise of transformation of material circumstances, the church offers the potential to transform the self[239]. Firstly, the ritual of deliverance offers a space in which members can articulate their problems, objectifying them as demonic forces, thus facilitating a clearer mapping of intrapsychic suffering[240]. Furthermore in its preoccupation with the past, rupture and renewal, Pentecostal practice may also offer a space in which adherents can reflect upon and bridge the gap between old and new ways of being (Meyer 1998a: 339)[241]. Above all, religious belief at TCPM is a deeply embodied process with ritual practices such as receiving anointing oil and glossolalia, being experienced as deeply satisfying and often resulting in feeling "uplifted" and the relief of suffering[242]. This embodied sense of transformation powerfully reinforces belief (Harris 2006) and when embedded within a network of shared practice leads to the formation of a *charismatic habitus* that predisposes adherents to the transformative

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[238] Tweed borrows from Appadurai's notion of "global cultural flows" and the notion of –scapes (1996) in order to specifically capture transnational religious flows in his ethnography of Cuban Catholics in Miami.

[239] The work of Thomas Csordas on the phenomenology of faith healing within the Charismatic Catholic Renewal Movement in the United States describes clearly the role of faith healing in addressing psychological suffering and pain (1997).

[240] Csordas writes of deliverance" "if the cosmological effect […] is to objectify evil spirits, the psychological effect is to formulate a problem which had previously eluded the patient. The identification of multiple spirits sets the stage for describing how spirits are interacting within the person, and thus provides a parapsychodynamic idiom for dealing with psychological conflicts" (1997 178).

[241] Also of interest here is Dan Sperber's work on the cognitive basis of religious belief in which he suggests that semi-propositional representational beliefs ("fuzzy" concepts which we don't fully grasp such as love or God, as opposed to factual beliefs) "gives us the means to process information […] which exceeds our conceptual capacities" (1985: 53).

[242] Some members described relief from physical ailments after practices such as healing or anointing. Csordas attributes this to an alteration of "somatic modes of attention" (1997: 67) in which adherents' orientation to physical symptoms are reconfigured. He cites the example of a man with chronic back pain who experienced a marked reduction in symptoms after faith healing, partly as a result of a renewed vigilance for onset of symptoms in order to offer prophylactic prayer (Ibid.: 68).

efficacy of deliverance and healing, as eloquently summarised by Csordas:

> "The sense of the divine other is cultivated by participation in a coherent ritual system. This ritual system is embedded in, and helps to continually create, a behavioural environment in which participants embody a coherent set of dispositions or habitus. These are the elements that constitute the webs of significance – or of embodied existence in which the sacred self comes into being. To be healed is to inhabit the Charismatic world of sacred self."
>
> (Csordas 1997: 24)

6.6 Medication, miracles and HIV

> "I have been suffering for years now and I decided to go for a test, at the hospital, it was confirmed that I had tested positive to HIV and I screamed as I thought it was the end of my life […] I became a recluse because of this and most of the time, I kept to myself […] I came for counselling and I didn't mention to the Pastor I had this disease. He blessed oil and Ribena for me and encouraged me that as long as I believe, God will terminate whatever sickness in my body. I became joyous and found myself enjoying every deliverance session for the week […] After one month, I noticed that I felt good within myself, I became more confident and I had the peace of God that surpasses all understanding. This kept me going and all my friends noticed the change in me […] I noticed I had more strength even after I had stopped the medication the doctors gave to me […] Church, I have to tell you the good news I have been to three different hospitals for test and glad to tell you that Jesus has washed all my sins away as all the three tests came out negative! As I speak now I am so happy because God has delivered me and a man is even knocking asking me to marry him."
>
> (Extract from TCPM "Daily Devotional Guide", December 2010)

So far in this chapter I have outlined the cosmological framework in which misfortune is addressed within the TCPM through the ritual practice of deliverance and I have explored the appeal of Pentecostalism using the notion of transformation. The extract above, entitled "My terminal sickness is gone, thanks to God of the TCPM", now brings me back to the central concern of this chapter. How is illness, especially HIV, addressed within Pentecostal churches such as the TCPM, and do Pentecostal beliefs serve as a barrier to engagement with HIV services and interventions?

Recovery from illness is one of the greatest and most desired transformations within the TCPM, and is a central preoccupation of members as demonstrated by the number of "testimonies", like the one above, describing divine healing[243]. Testimonies, public accounts by members of "miracles" they have experienced through deliverance and healing, form a large bulk of the main Sunday service at TCPM and are the main focus of television broadcasts[244]. Members are strongly encouraged to recount their experiences of transformation not only to the rest of the congregation but also to others that they meet:

> "It will be very unkind and ungrateful of you to keep the miraculous story of your deliverance to yourself. You should let others know, so that they may also pluck up enough courage to try God."
>
> (Extract from TCPM publication on deliverance, 2009)

Of the fifty-two testimonies I witnessed at TCPM services, just under a third (16) were related to health and illness. Along with testimonies about financial and employment success (14) and marriage and fertility (12), they were by far the most common subjects of testimonies in the church, reflecting the main targets of prayer within the TCPM namely marriage, fertility, immigration papers, financial success and health. Accounts of divine healing ranged from recoveries from serious injury and illness such as suspected cancer to the speedy resolution of relatively trivial ailments such as chest infections. Although I never witnessed an instance of healing during a church service, members discussed cases frequently and many described healing in their own lives manifesting in alleviation of physical symptoms.

Earlier in this chapter I described how misfortune is embedded within a larger moral universe defined by the spiritual battle between God and evil spirits. Deliverance aims to release adherents from the influence of malign spirits in order to enact

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[243] It is important to clarify the difference between deliverance and healing. Deliverance refers to being set free from the influence of evil spirits. Healing pertains specifically to the restoration of physical health whereas deliverance aims to secure spiritual wellbeing, although as discussed previously this can result in material transformation including healing.

[244] Testimonies serve a number of important functions within Pentecostalism. On an individual level, they are an opportunity for believers to further strengthen their personal relationship with God and give thanks for blessings received thus securing continued good favour. They contribute to the shaping of a charismatic habitus, providing an exemplar of embodiment and performance of Pentecostal Christianity. Finally, accounts of "miracles" at services are important evangelising tools as they are disseminated in the wider world through word of mouth and broadcast and print media. They have been instrumental in building the TCPM's reputation as a place of "amazing miracles [and] things you have never seen" as many members were initially drawn to the church either through hearing accounts of "miracles" from friends or watching testimonies on satellite television.

transformation in the “physical, spiritual, financial, matrimonial and emotional realms” (from TCPM service, 02 August 2011). Illness, like any other type of misfortune, is thought to ultimately have a spiritual aetiology necessitating deliverance. Direct comparisons are made between healing within the church and biomedicine, with the Pastor borrowing heavily from biomedical terminology describing Jesus as “the greatest physician” and the church as a “spiritual operating table” (TCPM service, 02 August 2011). Indeed, the superiority of God’s power over biomedicine is made explicit in assertions such as “no one has God’s pharmacy” (TCPM service, 02 August 2011), and the recounting of numerous cases of doctors’ failures to treat illnesses which were subsequently healed within the church. This is partly due to biomedicine’s inability to engage with spiritual aetiology:

“Unlike your General Practitioner who can attend to your medical problems to the exclusion of your other problems […] if we are afflicted medically, God would not only deliver us medically, but emotionally, spiritually and otherwise.”

(Extract from TCPM publication on deliverance, 2009)

Furthermore, God’s treatment is free making it accessible to all, especially the dispossessed:

“In some parts of the world where hospital treatment is not free, patients can be left in hospital corridors pending when their families can come up with the required funds for their treatment […] God’s deliverance costs nothing [...] God’s system is the only one for the down-and-out who have no hope in the world’s system.”

(Extract from TCPM publication on deliverance, 2009)

As described earlier, the Pentecostal world is one that is inherently insecure and vulnerable to evil forces, and members of the church are cautioned against mistrusting God’s power. “Negative reports” from a doctor could be the “Devil’s report” designed to instil fear and leave one open to demonic possession producing “sickness, diseases, weakness, failure” (Extract from TCPM publication on the power of words, 2009). However, despite the weight of expectation and spiritual imperative to pursue a divine solution to illness, at no time did I witness explicit directives by Pastors at the TCPM to their congregation to reject biomedicine[245].

I now wish to return to African women living with HIV in the UK, especially those who are pregnant, to understand the role churches such as TCPM may play in their lives. The hours devoted to prayers for “fruits of the womb” reveal how motherhood is constitutive of female identity within the church, with women who are unable to bear children commonly thought to be suffering from a spiritual affliction. For many women, being HIV-positive and not having children is doubly stigmatising and impacts on their sense of identity as women. Marriage, fertility and health are among the most prominent targets for miraculous healing within TCPM and the church therefore promises to deliver HIV-positive women from two assaults on their sense of self, HIV and childlessness, offering hope that they may be able to perform culturally sanctioned social roles. Once pregnant, regardless of HIV-status, the church becomes a sanctuary for expectant mothers where various rituals are enacted in order to ensure safe delivery of a healthy baby. For many women, pregnancy and early motherhood in the context of HIV is characterised by fear for their children’s health[246]. The promise of divine protection within TCPM therefore provides particular succour as described by Rhoda, an HIV-positive member of TCPM:

All the pregnant women come to the front [of the church] and you put anointing oil on you […] I believed that it’s protection if there was evil forces against me and stuff like that […] I was at peace and I thought that nothing would happen to this baby.

(Rhoda, member of the TCPM congregation)

Furthermore, there are explicit references during services and within church literature to divine healing of HIV, although this is often in the context of healing of a range of common illnesses including “diabetes, leukaemia, bowel cancer, insomnia, depression and high cholesterol” (TCPM service, 16 August 2011). Some participants had heard of or had met people with HIV who had been healed by God:

One lady just came [to church] and said she was diagnosed with HIV […] I said to myself ‘One day He will heal me like that lady’ [...] She prays and prays and all those things. So one day she went to a doctor for a test. The results came back; they said

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[245] Having not had one-to-one spiritual counselling I cannot exclude the possibility that members were advised to stop medication individually.

[246] Women's concerns about risks of transmission of HIV to their baby or possible toxicity of ART are discussed in Chapter Five.

'what is going on?' And they did [the HIV test] again and confirm that she's HIV free.

(Marie)

For people living with HIV, the greatest of transformations would be a cure, or as one woman put it "a total healing". This would mean release from a highly stigmatising chronic illness with its attendant demands including long term medication and anxieties about survival.

Clifford Geertz writes that religion acts to create order from disorder when:

"a tumult of events which lack not just interpretations but *interpretability* – threatens to break in upon man: at the limits of his analytic capabilities, at the limits of his powers of endurance, and at the limits of his moral insight."

(Geertz [2010] 1973: 100)

Religion may play an especially important bridging role in "limit situations" (Tweed 2008: 137) when people find themselves at the threshold of embodied existence, such as during illness. An HIV-positive diagnosis can be a "limit situation", throwing life into "tumult" and not readily interpretable. For many women interviewed, their HIV diagnosis had prompted a deep reflection on mortality, pushing them towards the threshold between life and death. Pentecostal belief and the promise of healing allowed them to mediate this space between the possible and impossible. Again, the central concept here is transformation, as women undertake spiritual healing in order to break with a past defined by their HIV-status. Furthermore, the belief in the spiritual aetiology of HIV places the locus of agency beyond oneself, as well as providing the framework for understanding this "limit situation"[247]. As migrant women living with HIV who are marginalised on many levels, attributing HIV to spiritual forces provides the means to absolve themselves of blame for a highly stigmatising disease that is subjected to particularly moralising discourse, and in doing may foster self-worth.

The belief in divine healing therefore functions as a source of great hope and strength in confronting the daily challenges of living with HIV. Some women spoke of how pastors assured them that prayer would eventually lead to divine healing; however they

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[247] Harris describes this as "external causation" and notes how it is an important aspect of both Yoruba and Pentecostal cosmology: "External causation offers a logical explanation for apparently random misfortune, integrating malaise into a system of meaning that fends off feelings of inadequacy, and lack of self-worth. Foreign perils are encompassed by the familiar; new fears are named by old labels; strange experience is reduced to the known" (2006: 79).

all denied being advised to stop taking ART. Some had heard of churches where pastors advised stopping medication for a range of illnesses but they were largely critical of this stance. For them, a belief in divine healing did not preclude the use of biomedicine. Instead, some participants concluded that whilst waiting for their "miracle", the safest course of action was to continue taking ART, whilst others believed that faith and ART worked together synergistically as a healing-complex[248]:

> *I need God and medication. It's like if you're sitting an exam. God may lead you to read something before the exam and then you can answer the question. But if you don't even carry the textbook...how do you do it?*
>
> (Bolade)

There are numerous outcomes to HIV-positive women's pursuit of divine healing within Pentecostal churches. Some people believe that they have been cured of HIV through divine healing, although I did not encounter anyone who believed this during my study[249]. Instead what was more widespread was the belief in other markers of divine intervention such as simplification of drug regimens[250], an undetectable viral load on treatment, continued health, and the safe delivery of an HIV-negative child. Women, many of whom had migrated from countries where maternal and child death due to HIV were commonplace, understandably saw this in itself as miraculous. Many saw God operating through healthcare professionals and antiretroviral therapy and also believed that the power of prayer would augment the efficacy of their medication in a similar way to the use of other ritual objects within TCPM to bridge the distance between self and God in order to harness divine power.

However, some women did not feel that they had experienced healing despite great personal investment in Pentecostalism. The focus on personal efficacy within TCPM and the widespread belief that "your time will come" if you pray hard enough can lead to a sense of personal failure if the longed for transformation does not materialise. Within the church prolonged misfortune is perceived to be a result of ongoing demonic

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[248] Also see Csordas on American Charismatics (1993: 28) and Engelke on Zimbabwean Apostolics (2004: 93) who both describe the compatibility and widespread use of biomedicine in Charismatic Christianity.

[249] I have encountered a small number of patients who believe they have been cured of HIV in my clinical practice and discontinue treatment, however this does not appear to be common during pregnancy. The desire to secure an HIV-negative baby is likely to be an important motivation for women to continue their medication during pregnancy as discussed in Chapter Five.

[250] Treatment simplification is the change from multiple tablets to a regimen with fewer pills. As HIV medicine has evolved increasing numbers of co-formulated drugs (where multiple agents are combined in one tablet) have become available.

influence and evidence of a weak spiritual battle. One pastor at an AIC church in London described HIV as posing particular challenges to those seeking deliverance. Firstly, medical technology limits biomedicine's ability to assess whether someone has been cured:

> *You know with other medical conditions, when people are prayed for and they are healed, they go and do a biopsy on them or do a blood test on them and say 'OK the levels have changed, or whatever'. But with HIV we still don't have anything other than checking the viral load.*
>
> (Pastor of an AIC church in London)

For this Pastor, relying on a test that states that a person has undetectable levels of virus but that the virus is still present prevents confirmation of divine healing. Secondly she felt that some people living with HIV would not be cured despite intensive engagement with deliverance rituals and strong faith. Her interpretation was that God had his reasons and this should be accepted without questioning, yet she was concerned that HIV was often interpreted within churches as a "rod from God", a specific punishment for past sins that was not amenable to divine intervention.

However, the women in my study were not prepared to accept HIV as a "rod from God" and actively engaged in seeking healing from HIV and for other misfortunes. I will now conclude with a vignette as an illustrative example.

6.6.1 Rhoda

Rhoda was in her forties and had moved to the UK from Malawi in 1988 to join her husband. In 1992 he fell ill and died of an HIV-related illness. Shortly afterwards, Rhoda became unwell herself. She was subsequently diagnosed with HIV and informed that her prognosis was poor. Living in the UK on her own, she had found it hard to manage her grief for her husband and her anxieties about her future. She had been brought up a Catholic but had friends who were involved in Charismatic Catholic Churches. Aware of the emphasis on healing in these churches she decided to attend a Charismatic service and described herself as finding "so, so much peace" there. Over the course of twenty years she attended a variety of Pentecostal churches, attracted by their "energetic" modes of worship but always moving if she felt she was not obtaining desired results. An unemployed single mother, Rhoda's most recent concerns were no longer her health but her poor housing and precarious finances. A few years ago she had become drawn to the TCPM:

"I was watching the TV and I saw TCPM. I'm looking for a job, I need serious prayer so I said I'll go for deliverance."

She had found peace and strength through going there saying:

"I think it's the testimonies [...] I feel there is power in that Church."

Reflecting on nearly twenty years of living with HIV, Rhoda believed that her faith and religious practice had mobilised God's power through both deliverance *and* the work of her doctors, and that her divine healing had manifested in her continued good health and that of her daughter.

Rhoda was typical of many women I spoke to in that she had attended numerous churches, both charismatic and non-charismatic, to seek a desired outcome, whilst continuing to engage with biomedicine. In his description of the increasing commodification and diversity of religious faith in North America, Roof introduces us to the "spiritual marketplace" (Roof 2001). With the rapid expansion of the Pentecostal faith globally, and the growing number of churches in London alone competing for members using increasingly sophisticated means, people are free to choose a church that they feel will cater to their needs[251]. Furthermore, African women living with HIV in London are situated within a plural healthscape populated by biomedicine and a wide range of religious institutions, with a belief in divine healing an important but not singular resource in securing health and well–being. Pentecostal faith did not serve as barrier to engaging with HIV services and interventions for the women in my study. There was no epistemological rupture in holding these two beliefs together as, for many women, the mechanisms of healing were of secondary consequence to efficacy (Last 1981). Whyte writes of the "pragmatics of uncertainty" (1997); when confronted with misfortune her participants in Uganda tried out various systems of healing ranging from divination to biomedicine. The pursuit of alleviation of suffering was open-ended, with doubt inherent in all systems and outcomes indeterminate, allowing people to retain hope that if one system fails, then another may be effective. Thus taking ART whilst striving for a divine healing is ultimately a pragmatic approach to make (in the words of

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[251] Read's ethnography of approaches towards mental illness in rural Ghana highlights the widespread hope among patients and their families for miraculous cures. However, the longed for cure often did not materialise. The ensuing scepticism was not directed towards miracles themselves, but towards the practitioners who had failed to deliver on their promise (2012).

one of my participants) “the impossible become possible”.

6.7 Conclusions

In this chapter I have drawn upon observations from ethnographic fieldwork conducted at a diasporic Nigerian Pentecostal church on the outskirts of London. As such, it is difficult to generalise to other Pentecostal churches in London with confidence, although my findings resonate with those of other authors who have conducted fieldwork in Pentecostal churches in a diverse range of settings (van Dijk 1997, Meyer 1998a, Coleman 2000, Hunt 2002, Engelke 2004, Harris 2006, Adogame 2007).

The impact of divine healing on engagement with HIV care has become increasingly of concern among professionals working within HIV, with a narrative of exploitation and harm within diasporic African Pentecostal churches emerging of late in sections of the British media. In this chapter I have challenged these dominant negative representations of Pentecostalism within African migrant communities by exploring how migrant Africans, including pregnant women living with HIV, actively engage with and use Pentecostal faith as a cultural resource in managing illness. Adherents to Pentecostalism exist in a universe where *all* misfortune (ranging from immigration concerns to illness) is a demonic affliction necessitating spiritual warfare through a range of rich ritual practice centred on the power of the Word and the promise of transformation. The belief in divine intervention and the discourse of transformation can foster hope and self-efficacy in the face of an incurable illness, whilst also serving to reduce stigma by attributing causation to an external force. Furthermore, spiritual practice within the TCPM is deeply embodied by members and is a source of great personal empowerment and satisfaction. Finally, the pragmatic orientation of TCPM and its willingness to engage with its congregation’s real life problems is part of its appeal as it recognises and addresses the social marginalisation faced by some of its members, providing the protection of a surrogate family and material assistance in times of hardship.

There are valid critiques to be made of TCPM and churches similar to it. The TCPM has been able to expand rapidly into a multi-million pound business empire within the space of a few years, currently running at significant profit. Much of this comes in the forms of tithes from their members, some of whom are poverty-stricken and hoping for salvation from their current predicament. However, in the course of my fieldwork I did not encounter anyone who had been adversely affected by their Pentecostal beliefs, nor did I find any evidence of Pentecostal faith as a pervasive barrier to engagement with HIV care. The HIV-positive pregnant women I interviewed were extremely pragmatic and outcome-driven in their quest to secure a better future for themselves and their babies. They occupied a plural healthscape populated by biomedicine and an array of Pentecostal churches, and were willing to draw upon a number of resources when managing life with HIV, with a belief in divine healing *not* precluding the use of ART. Instead their search for divine healing was often part of a larger quest to find solutions to multiple misfortunes, with their faith representing a vital source of hope, succour and resilience.

Key points

- Pentecostal Christianity (characterised by a direct personal experience of God and spiritual gifts such as speaking in tongues and divine healing) is one of the fastest growing religions both globally and in the UK.

- The TCPM is an example of a rapidly expanding diasporic Nigerian Pentecostal churches with branches in London and elsewhere in the UK.

- The TCPM, in line with conventional Pentecostal teachings, constructs a universe where misfortune, including illness, is caused by demonic forces that require battle within the spiritual plane.

- Pentecostalism may hold particular appeal for migrants due to its pragmatic engagement with adherents' problems.

- Pentecostal cosmology and the promise of transformation can foster a sense of self-efficacy and hope, whilst at the same time reducing self-stigma by attributing misfortune to an external agent.

- However, the vast majority of members use their church as one of a variety of resources in their healthscape in a pragmatic quest for a better future for themselves and their babies.

7

Engaging with health services during pregnancy

Summary

In this chapter I focus on African HIV-positive women's engagement with, and experience of, health services during pregnancy. This second mixed methods chapter of the thesis uses data from the NSHPC to examine the relationship between maternal ethnicity, African region of birth and duration of residence in the UK, and late antenatal booking. These quantitative findings are contextualised with ethnographic data exploring women's attitudes towards and experiences of health services. I also draw upon ethnographic data to specifically explore women's experiences of maternity services at the time of delivery, an aspect of care that is not captured by surveillance data. By weaving together these different strands, I aim to describe in detail African HIV-positive women's use and experience of health services in the UK during pregnancy.

7.1 Introduction

In Chapter Five I explored the use of ART in pregnancy by African women living with HIV, concluding that most engaged well with treatment during pregnancy. For a minority, important challenges included stigma and structural factors such as poverty, homelessness and lack of UK citizenship rights. In Chapter Six, I challenged the perception of Pentecostal Christianity as a major barrier to taking ART, describing women's pragmatic deployment of faith as part of a broader cultural system that addresses misfortune. In this chapter I shift my focus from the use of ART to engagement with and experience of health services during pregnancy. This is an aspect of HIV care that has been relatively overlooked in the literature on HIV and pregnancy as discussed in Chapter Two.

When an HIV-positive woman becomes pregnant her engagement with clinical services will differ from that of an HIV-negative pregnant woman. In the UK, pregnant women living with HIV are expected to attend a hospital-based antenatal clinic at least once or twice a month, ideally to be seen by a specialist multidisciplinary team including an HIV physician, an HIV specialist midwife, an obstetrician and a paediatrician (Taylor et al. 2012). In contrast, most pregnant women without complications will be seen between seven to ten times during their pregnancy, mainly by a midwife and often not in a hospital setting (National Institute for Health and Clinical Excellence 2008). During these numerous visits to the antenatal clinic, HIV-positive women have regular blood test monitoring, whilst the clinical team discuss options for mode of delivery and provide guidance about infant feeding. HIV antenatal care also serves an additional function in that it presents an important opportunity to engage women in longer-term care, facilitating their return for follow-up after pregnancy. Little is currently known about women's use of HIV services during pregnancy, with even less work exploring women's experiences. This is a critical aspect of HIV and pregnancy, as experiences of clinical services during pregnancy are likely to influence how women access care and manage their HIV later in pregnancy and in the longer term.

In this mixed methods chapter I first draw upon NSHPC data to examine late antenatal booking and its relationship with maternal ethnicity, African region of birth and duration of residence in the UK. I then contextualise these quantitative findings with ethnographic data, mainly originating from my interviews within NHS clinics, in order to explore women's attitudes towards and experiences of clinical services. Finally I draw exclusively upon ethnographic data to specifically describe women's experiences of maternity services around the time of delivery.

7.2 Epidemiological data on late antenatal booking[252]

UK guidelines state that all women should have their first antenatal care appointment, known as "antenatal booking", by ten to thirteen weeks' gestation (National Institute for Health and Clinical Excellence 2008, Department of Health 2009). In the context of maternal HIV infection, timely initiation of antenatal care allows for early screening for maternal HIV infection (if a woman is not already diagnosed), prompt initiation of ART, planning of infant delivery and advice regarding avoidance of breastfeeding, all of which contribute to maternal and child health and minimisation of the risk of vertical transmission. In this section I explore the association between late antenatal booking and: (i) maternal ethnicity, (ii) maternal African region of birth, and (iii) maternal duration of residence in the UK at conception (for African women).

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[252] Some of this material appears in Tariq et al. 2012a.

The analysis was restricted to pregnancies with an actual date of delivery between January 2008 (when antenatal booking date started to be routinely collected by the NSHPC) and December 2010 or with an expected date of delivery (EDD) between those dates if the outcome was not a live or stillbirth. Ectopic pregnancies and terminations of pregnancy (n=78) were excluded, as it is unlikely that antenatal care would have been sought or indicated. Use of ART at conception was categorised as “yes with viral load <50 copies/ml”, “yes with viral load ≥ 50 copies/ml” and “no”[253]. The analysis was stratified by whether a woman had been diagnosed with HIV (i) prior to or (ii) during the reported pregnancy, as these groups were not felt to be comparable. There were few sequential pregnancies during this time period (270/3355) and therefore robust standard errors were not used. EDD/year of delivery and parity were included in multivariable models *a priori* as confounders. Other potential confounding variables considered included maternal age, history of injecting drug use, ART at conception, first CD4 in pregnancy and reporting region.

“Early” booking was defined as reported antenatal booking before thirteen complete weeks’ gestation. “Late” booking was defined as booking at thirteen weeks or more complete weeks’ gestation. This analysis excludes pregnancies in women who arrived in the UK after conception (n=87) as they would have been unlikely to have had the opportunity to access antenatal care during the first trimester[254] of pregnancy. The analysis was stratified by whether a woman had been diagnosed with HIV prior to or during the reported pregnancy.

7.2.1 Results

There were 3355 eligible pregnancies with a delivery date or expected delivery date between January 2008 and December 2010. This analysis was based on 2481/3355 (74.0%) pregnancies with data available on antenatal booking in 2349 women. Missing antenatal booking date was associated with miscarriage, premature delivery, earlier time period and reporting region outside of London, (all p<0.001). There was also an association between both white ethnicity and Eastern and Southern African region of origin and missing booking date (p<0.05). Demographic and clinical characteristics of the study population are presented in table 7.1. Nearly 90% (89.1%) of pregnancies

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[253] I created this composite variable as baseline viral load and ART at conception were collinear (correlation coefficient = -0.67). The first viral load available during the reported pregnancy was used to create this variable.

[254] Pregnancy is grouped into three trimesters. The first trimester corresponds to week 1-12, the second to week 13-28 and the third to week 29 and beyond.

were in women who were of African ethnicity.

Overall, antenatal booking was late (≥13 weeks' gestation) in 46.8% (1162/2481; 95% confidence interval [CI]: 44.9%, 48.8%) of pregnancies, including 3.7% (92/2481; 95% CI: 3.0%, 4.5%) during the third trimester (≥28 weeks). Of those booking late, the median gestational week of booking was 16.4 (interquartile range 14.3-20.4 weeks). Time of booking varied with timing of maternal HIV diagnosis. Antenatal booking was late in 55.1% (357/648; 95% CI: 51.3%, 58.9%) of pregnancies in women diagnosed with HIV during the reported pregnancy compared with 43.9% (805/1833; 95% CI: 41.6%, 46.2%) of those in women diagnosed before the reported pregnancy ($p<0.001$).

On univariable analysis there was no evidence of an association between timing of booking and maternal age, injecting drug use or earliest CD4 count in pregnancy (all $p>0.1$, table 7.1) either in women diagnosed before or during the pregnancy. Year of EDD/delivery and reporting region were associated with late antenatal booking in both sub-groups ($p<0.001$). Parity of 0 or 3 was associated with late booking, compared with parity of 1 or 2, in those diagnosed prior to the reported pregnancy (χ^2_{trend} test $p<0.001$). Among this group, late booking was also associated with not being on antiretroviral therapy at conception or having a detectable viral load on treatment at conception ($p<0.001$).

There was an association between maternal ethnicity and timing of antenatal booking. In pregnancies where a woman was diagnosed with HIV prior to the reported pregnancy, 44.9% (736/1641) of African women booked late compared with 35.9% (69/192) of white British women ($p<0.05$). This association was also seen in the group diagnosed during the reported pregnancy, with nearly 60% of African women (327/570) booking late for antenatal care compared with 38.5% (30/78) of white British women ($p<0.05$). After adjusting for year of EDD/delivery, ART at conception, parity and reporting region, African ethnicity was associated with increased odds of late booking in women diagnosed with HIV *prior* to the reported pregnancy compared with white women (adjusted odds ratio [AOR] 2.03; 95% CI: 1.22, 3.40); $p<0.05$, table 7.2). In the group diagnosed *during* the reported pregnancy the odds of late booking were also increased in women of African ethnicity (AOR 1.81; 95% CI: 1.04, 3.15; $p<0.05$, table 7.2), when adjusted for year, parity and reporting region.

Restricting the analysis to African women, there was no association either on univariable or multivariable analysis (adjusting for year, ART at conception, parity and reporting region) between African region of origin and late booking among those diagnosed with HIV prior to the reported pregnancy (all *p*>0.1, table 7.3). Looking at pregnancies in women diagnosed during the reported pregnancy, the odds of booking late were increased in both Southern African women (AOR 1.76; 95% CI 0.95, 3.25; p=0.073, table 7.3) and Middle African women (AOR 2.08; 95% CI: 0.98, 4.40; p=0.056, table 7.3) compared with Eastern African women (adjusting for year, parity and reporting region), although this was of borderline significance.

Among African women who had been diagnosed with HIV before the reported pregnancy, a greater proportion of those who had arrived in the UK less than four years before conception (49.3%; 102/207) booked late compared with those who had been in the UK longer (42.5%; 366/862; *p*=0.076, table 7.4). After adjusting for year, ART at conception, parity and reporting area women who had arrived in the UK less than four years prior to conception still had increased odds of booking late, although this was of borderline significance (AOR 1.34; 95% CI: 0.97, 1.85; *p*=0.080, table 7.4). There was no evidence of an association between duration of residence in the UK and late booking among those diagnosed during the reported pregnancy after adjusting for year, parity and reporting region (AOR 0.68; 95% CI 0.43, 1.09; *p*>0.1, table 7.4).

Table 7.1: Demographic and clinical characteristics of women with pregnancies reported to the NHSPC by timing of antenatal booking, 2008-2010

	Diagnosed with HIV prior to reported pregnancy			Diagnosed with HIV during reported pregnancy		
	ANC booking <13 weeks, n (row %) n=1028	ANC booking ≥13 weeks, n (row %) n=805	*p*-value[a]	ANC booking <13 weeks, n (row %) n=291	ANC booking ≥13 weeks, n (row %) n=357	*p*-value[a]
Ethnicity						
White British	123 (64.1)	69 (35.9)	0.019	48 (61.5)	30 (38.5)	0.002
African	905 (55.2)	736 (48.9)		243 (42.6)	327 (57.4)	
African region of birth*						
Eastern Africa	571 (56.4)	441 (43.6)	0.302	135 (45.8)	160 (54.2)	0.072
Southern Africa	47 (47.5)	52 (52.5)		21 (33.9)	41 (66.1)	
Western Africa	200 (55.1)	163 (44.9)		76 (43.9)	97 (56.1)	
Eastern Africa	87 (52.1)	80 (47.9)		11 (27.5)	29 (72.5)	
Duration of residence in the UK*						
≥4 years	496 (57.5)	366 (42.5)	0.076	66 (38.8)	104 (61.2)	0.107
<4 years (before conception)	105 (50.7)	102 (49.3)		73 (47.7)	80 (52.3)	
Maternal age at delivery						
<25 years	77 (59.7)	52 (40.3)	0.596	43 (44.8)	53 (55.2)	0.606
25-34 years	550 (56.9)	417 (43.1)		168 (46.5)	193 (53.5)	
≥35 years	332 (55.2)	270 (44.9)		50 (41.3)	71 (58.7)	
Year of EDD/delivery						
2008	215 (48.2)	231 (51.8)	<0.001[b]	78 (34.7)	147 (65.3)	<0.001[b]
2009	377 (55.7)	300 (44.3)		127 (52.7)	114 (47.3)	
2010	436 (61.4)	274 (38.6)		86 (47.3)	96 (52.8)	
IDU						
No	1020 (56.0)	802 (44.0)	0.265	291 (45.1)	354 (54.0)	0.117
Yes	8 (72.7)	3 (27.3)		0 (0.0)	3 (100.0)	

Table 7.1 continued

	Diagnosed with HIV prior to reported pregnancy			Diagnosed with HIV during reported pregnancy		
	ANC booking <13 weeks, n (%) n=1028	ANC booking ≥13 weeks, n (%) n=805	*p*-value[a]	ANC booking <13 weeks, n (%) n=291	ANC booking ≥13 weeks, n (%) n=357	*p*-value[a]
Earliest CD4 count[¶], cells/µl						
≥350	655 (57.9)	476 (42.1)	0.106	130 (42.3)	177 (57.7)	0.447
200-249	235 (54.0)	200 (46.0)		83 (47.4)	92 (52.6)	
<200	74 (50.0)	74 (50.0)		49 (40.8)	71 (59.2)	
ART at conception						
Yes with earliest VL<50 copies/ml	510 (61.0)	326 (39.0)	<0.001	N/A	N/A	
Yes with earliest VL ≥50 copies/ml	81 (53.6)	70 (46.4)				
No	370 (48.9)	386 (51.1)				
Parity						
0	231 (66.6)	116 (33.4)	<0.001	135 (44.6)	168 (55.5)	0.569
1	381 (56.0)	300 (44.1)		87 (46.0)	102 (54.0)	
2	234 (53.3)	205 (46.7)		32 (38.1)	52 (61.9)	
3	114 (45.2)	138 (54.8)		18 (50.0)	18 (50.0)	
Reporting areas						
London	434 (58.0)	314 (42.0)	0.013	82 (34.8)	154 (65.3)	0.001
England (not London)	401 (52.8)	359 (47.2)		138 (50.7)	134 (49.3)	
Scotland, Wales, NI	42 (44.2)	53 (55.8)		18 (41.9)	25 (58.1)	

[a]Obtained using χ^2 test; [b]obtained using χ^2 test for trend; *restricted to African women; ¶first reported value in pregnancy. ANC, antenatal care; EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use; ART, antiretroviral therapy; N/A, not applicable.

Table 7.2: Univariable and multivariable analysis of the association between maternal ethnicity and late booking during pregnancy

	Diagnosed with HIV prior to reported pregnancy				Diagnosed with HIV during reported pregnancy			
	Univariable analysis		*Multivariable analysis, n=1469*		*Univariable analysis*		*Multivariable analysis, n=525*	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Ethnicity								
White British	1.00		1.00		1.00		1.00	
African	1.45 (1.06,1.98)	0.018	2.03 (1.22,3.40)	0.007	2.15 (1.33,3.50)	0.002	1.81 (1.04,3.15)	0.037
Maternal age at delivery								
<25 years	1.00	0.595			1.00	0.007		
25-34 years	1.12 (0.77,1.63)				0.93 (0.59,1.47)			
≥35 years	1.20 (0.82,1.77)				1.15 (0.67,1.98)			
Year of EDD/delivery								
2008	1.00	<0.001	1.00		1.00	<0.001	1.00	
2009	0.74 (0.58,0.94)		0.83 (0.64,1.09)	0.181	0.48 (0.33,0.69)		0.50 (0.33,0.77)	0.002
2010	0.58 (0.46,0.74)		0.59 (0.45,0.77)	<0.001	0.59 (0.40,0.88)		0.57 (0.36,0.90)	0.016
Earliest CD4 count¶, cells/µl								
≥350	1.00	0.107			1.00	0.448		
200-249	1.17 (0.94,1.46)				0.81 (0.56,1.18)			
<200	1.38 (0.98,1.94)				1.06 (0.69,1.63)			
ART at conception								
Yes with earliest VL<50 copies/ml	1.00	<0.001	1.00		N/A		N/A	
Yes with earliest VL ≥50 copies/ml	1.35 (0.95,1.92)		1.32 (0.91,1.94)	0.147				
No	1.63 (1.34,1.99)		1.68 (1.34,2.10)	<0.001				
Parity								
0	1.00	<0.001	1.00		1.00	0.567	1.00	
1	1.57 (1.20,2.05)		1.66 (1.23,2.24)	0.001	0.94 (0.65,1.36)		1.06 (0.70,1.61)	0.766
2	1.74 (1.30,2.33)		1.82 (1.31,2.52)	<0.001	1.31 (0.80,2.14)		1.62 (0.91,2.89)	0.101
3	2.41 (1.73,3.37)		2.71 (1.86,3.95)	<0.001	0.80 (0.40,1.60)		0.98 (0.46,2.07)	0.951

Table 7.2 continued

	Diagnosed with HIV prior to reported pregnancy				Diagnosed with HIV during reported pregnancy			
	Univariable analysis		*Multivariable analysis, N=1469*		*Univariable analysis*		*Multivariable analysis, n=525*	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Reporting areas								
London	1.00	0.013	1.00		1.00	0.001	1.00	
England (not London)	1.24 (1.01,1.52)		1.31 (1.05,1.64)	0.016	0.52 (0.36,0.74)		0.54 (0.37,0.80)	0.002
Scotland, Wales, NI	1.74 (1.13,2.68)		1.98 (1.23,3.18)	0.005	0.74 (0.38,1.43)		0.87 (0.42,1.79)	0.701

¶First reported value in pregnancy. OR, odds ratio; CI, confidence interval; AOR, adjusted odds ratio: EDD, expected date of delivery; ART, antiretroviral therapy; VL, viral load; NI, Northern Ireland.

Table 7.3: Univariable and multivariable analysis of the association between maternal African region of birth and late booking during pregnancy (restricted to African women)

	Diagnosed with HIV prior to reported pregnancy				**Diagnosed with HIV during reported pregnancy**			
	Univariable analysis		***Multivariable analysis, n=1312***		***Univariable analysis***		***Multivariable analysis, n=537***	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
African region of birth								
Eastern Africa	1.00		1.00		1.00		1.00	
Southern Africa	1.43 (0.95,2.17)	0.088	1.42 (0.86,2.32)	0.169	1.65 (0.93,2.92)	0.088	1.76 (0.95,3.25)	0.073
Western Africa	1.06 (0.83,1.34)	0.662	1.22 (0.92,1.62)	0.174	1.08 (0.74,1.57)	0.701	1.16 (0.77,1.75)	0.468
Middle Africa	1.19 (0.86,1.65)	0.297	1.19 (0.82,1.74)	0.366	2.22 (1.07,4.61)	0.032	2.08 (0.98,4.40)	0.056
Maternal age at delivery								
<25 years	1.00	0.236			1.00	0.371		
25-34 years	1.35 (0.86,2.13)				0.81 (0.46,1.42)			
≥35 years	1.48 (0.93,2.36)				1.09 (0.57,2.06)			
Year of EDD/delivery								
2008	1.00	<0.001	1.00		1.00	0.005	1.00	
2009	0.77 (0.60,0.99)		0.90 (0.67,1.19)	0.449	0.54 (0.36,0.80)		0.55 (0.37,0.84)	0.005
2010	0.58 (0.45,0.74)		0.60 (0.45,0.80)	0.001	0.59 (0.39,0.91)		0.66 (0.43,1.04)	0.071
Earliest CD4 count[¶], cells/μl								
≥350	1.00	0.183			1.00	0.176		
200-249	1.20 (0.95,1.52)				0.68 (0.46,1.02)			
<200	1.27 (0.89,1.81)				0.90 (0.58,1.41)			
ART at conception								
Yes with earliest VL<50 copies/ml	1.00	<0.001	1.00		N/A		N/A	
Yes with earliest VL ≥50 copies/ml	1.36 (0.94,1.95)		1.30 (0.87,1.93)	0.199				
No	1.65 (1.33,2.03)		1.58 (1.24,2.00)	<0.001				

Table 7.3 continued

	Diagnosed with HIV prior to reported pregnancy				Diagnosed with HIV during reported pregnancy			
	Univariable analysis		*Multivariable analysis, n=1312*		*Univariable analysis*		*Multivariable analysis, n=537*	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Parity								
0	1.00	<0.001	1.00		1.00	0.375	1.00	
1	1.57 (1.17,2.10)		1.73 (1.24,2.40)	0.001	0.88 (0.60,1.29)		0.92 (0.62,1.38)	0.700
2	1.73 (1.26,2.36)		1.91 (1.34,2.70)	<0.001	1.46 (0.84,2.53)		1.55 (0.88,2.71)	0.128
3	2.17 (1.52,3.09)		2.59 (1.74,3.87)	<0.001	0.97 (0.44,2.14)		1.08 (0.49,2.41)	0.845
Reporting areas								
London	1.00	0.236	1.00		1.00	0.037		
England (not London)	1.34 (1.08,1.66)		1.44 (1.13,1.83)	0.003	0.61 (0.42,0.89)			
Scotland, Wales, NI	1.48 (0.90,2.45)		1.46 (0.85,2.51)	0.175	0.88 (0.38,2.02)			

¶First reported value in pregnancy. OR, odds ratio; CI, confidence interval; AOR, adjusted odds ratio: EDD, expected date of delivery; ART, antiretroviral therapy; VL, viral load; NI, Northern Ireland.

Table 7.4: Univariable and multivariable analysis of the association between maternal duration of residence in the UK at conception and late booking during pregnancy (restricted to African women)

	Diagnosed with HIV prior to reported pregnancy				Diagnosed with HIV during reported pregnancy			
	Univariable analysis		*Multivariable analysis, n=997*		*Univariable analysis*		*Multivariable analysis, n=313*	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Duration of residence in UK								
≥ 4 years	1.00		1.00		1.00		1.00	0.108
< 4 years (before conception)	1.32 (0.97,1.78)	0.076	1.34 (0.97,1.85)	0.080	0.70 (0.45,1.08)	0.107	0.68 (0.43,1.09)	
Maternal age at delivery								
<25 years	1.00	0.197			1.00	0.782		
25-34 years	1.47 (0.85,2.52)				0.96 (0.48,1.92)			
≥35 years	1.64 (0.94,2.84)				1.18 (0.53,2.59)			
Year of EDD/delivery								
2008	1.00	0.007	1.00		1.00	0.036	1.00	
2009	0.69 (0.50,0.93)		0.69 (0.50,0.95)	0.025	0.54 (0.32,0.92)		0.56 (0.32,0.96)	0.034
2010	0.61 (0.44,0.83)		0.59 (0.43,0.83)	0.002	0.54,0.31,0.96)		0.54 (0.30,0.97)	0.038
Earliest CD4 count[¶], cells/µl								
≥350	1.00	0.482			1.00	0.087		
200-249	1.05 (0.79,1.40)				0.59 (0.35,0.99)			
<200	1.34 (0.83,2.15)				0.62 (0.35,1.11)			
ART at conception								
Yes with earliest VL<50 copies/ml	1.00	0.001	1.00		N/A		N/A	
Yes with earliest VL ≥50 copies/ml	1.34 (0.86,2.09)		1.31 (0.83,2.07)	0.248				
No	1.62 (1.25,2.11)		1.56 (1.19,2.05)	0.001				

Table 7.4 continued

	Univariable analysis		*Multivariable analysis, n=997*		*Univariable analysis*		*Multivariable analysis, n=313*	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**OR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Parity								
0	1.00	0.002	1.00		1.00	0.409	1.00	
1	1.48 (1.02,2.14)		1.57 (1.07,2.30)	0.021	0.80 (0.48,1.34)		0.82 (0.49,1.39)	0.466
2	1.56 (1.05,2.32)		1.72 (1.14,2.58)	0.009	1.50 (0.70,3.18)		1.44 (0.67,3.11)	0.348
3	2.36 (1.52,3.68)		2.56 (1.62,4.03)	<0.001	0.72 (0.28,1.82)		0.72 (0.27,1.88)	0.501
Reporting areas								
London	1.00	0.112			1.00	0.123		
England (not London)	1.29 (0.99,1.69)				0.64 (0.39,1.04)			
Scotland, Wales, NI	1.52 (0.77,2.98)				1.41 (0.42,4.72)			

¶First reported value in pregnancy. OR, odds ratio; CI, confidence interval; AOR, adjusted odds ratio: EDD, expected date of delivery; ART, antiretroviral therapy; VL, viral load; NI, Northern Ireland.

7.2.2 Summary of epidemiological analysis of late antenatal booking

Nearly 50% of women diagnosed with HIV present to antenatal care beyond thirteen weeks of pregnancy, with African women being at higher risk of late booking than white British women. I also found an association between late antenatal booking and Southern and Middle African region of birth and, for those diagnosed with HIV before the reported pregnancy, duration of residence in the UK, although these were of borderline significance. It is hard to make comparisons with other studies as firstly there is no clear consensus on the definition of late antenatal booking and secondly the current UK target of before thirteen weeks' gestation has only been introduced within the past three years. However, the proportion of pregnancies in which booking was late in this analysis appears to be higher than in the overall antenatal population in England where late booking has been estimated at approximately 30%[255]. It is also higher than rates of antenatal booking reported previously in HIV-positive women (Parisaei et al. 2007, Jasseron et al. 2008). The association between migrant African ethnicity and late antenatal booking has previously been reported in the context of HIV in France (Jasseron et al. 2008). It also reflects the well-documented association between ethnicity, migration and late booking seen among pregnant women in general[256].

The impact of missing data on these analyses has been discussed in Chapter Three. The analyses were limited by small numbers in comparison to the other analyses presented in this thesis as a result of booking date not being routinely collected by the NSHPC until 2008. Furthermore, when booking dates were recorded it was difficult to be certain that this date corresponded to antenatal booking and not when the woman first attended the HIV antenatal service, which may be some time later[257].

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[255] Data obtained from NHS maternity statistics tables 2010-2011, England, available at http://www.hscic.gov.uk/pubs/maternity1011 (accessed 23 September 2013).

[256] See Chapter Two for a detailed overview of literature on ethnicity, migration and antenatal booking.

[257] Discussions with clinical colleagues revealed a lack of clarity regarding what constituted booking date and the fact that this date may not be easily available at the time of completing notification forms.

7.3 Ethnographic data on antenatal booking

The analysis of national surveillance data has revealed that nearly 50% of women living with HIV book late for antenatal care in the UK with African women more likely to book late than white British women. Late antenatal booking was not only common in women who were diagnosed with HIV *during* their pregnancy, and therefore unaware of their HIV status at the time of booking, but was also common in those who already knew their HIV status. These findings draw attention to an apparent disparity in access to antenatal care among HIV-positive women. Why is it that women living with HIV present late for antenatal care, and why are African women in particular more likely to book late?

7.3.1 Engaging with antenatal care

The majority of women who I interviewed (21/24) had presented to antenatal services before the end of their first trimester[258]. As discussed in Chapter Five, African women in diaspora are situated within a transnational *healthscape*, having had extensive experience of biomedicine in their home countries. My participants had predominantly come from urban elite settings where biomedicine carries prestige and cultural capital[259]. Many had been pregnant before in Africa, and had sought hospital care during those pregnancies and antenatal care was therefore not a novel intervention.

Women were also highly motivated to attend for antenatal care in the context of HIV, in much the same way as they were motivated to take ART as described in Chapter Five. To be a good mother entails securing a healthy HIV-negative baby and many women were anxious to attend for care early to ensure they were on the correct medication. Furthermore, as Browner and Press highlight in their study of prenatal care in the US (1997), women often find emotional reassurance through regular attendance and see technological interventions such as foetal ultrasound and stethoscope as a tool to forge intimacy with their unborn child. This may have even more salience in the context of HIV, as touched upon in Chapter Five. Women may perceive their HIV-positive pregnant bodies, carrying a risk of transmitting HIV and the potential toxicity of ART, as unreliable and requiring surveillance and monitoring. Antenatal care therefore offers

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[258] This is, of course, a reflection of the fact that women who engaged well with care were also likely to be more willing to participate in this study.

[259] Bourdieu's concept of cultural capital extends the notion of capital beyond the economic sphere and into the sphere of culture. Groups are defined and define themselves through a constellation of symbolic practices involved in the consumption of culture such as tastes in music, fashion and art (Bourdieu 1986). Here I see biomedicine as a cultural resource whose consumption marks groups as elite.

an opportunity for regular blood testing to monitor their clinical condition and foetal ultrasound scanning to check their baby's wellbeing in the context of HIV and ART exposure.

Women generally described the care they received from their HIV antenatal team in positive terms. It was clear from these discussions that women particularly valued the fact that their healthcare professionals proactively situated their pregnancy in their daily lives, understanding the exigencies of lives often being lived in the margins. For many, pregnancy was overshadowed by the oppressive realities of poverty, poor housing, food insecurity and insecure immigration status. Attending antenatal care was an important step towards accessing practical support, especially if they had not been engaged in HIV care prior to their pregnancy, and was often the first time a professional had attended to their social needs. This fits into Mol's "logic of care" (2008) as outlined in Chapter Five, in which illness is addressed empathically and is situated within a broader context. Some women drew direct comparisons between the care they received by their specialist teams, and other clinical services they had come into contact with during their pregnancy. Women were wary of interactions with non-specialist staff who often had limited knowledge of HIV and pregnancy, finding them poorly informed or judgemental. In contrast, within the HIV antenatal clinic women felt that they were given time and support to understand pregnancy in the context of HIV without fear of being stigmatised, the interpersonal relationships with staff being defined by care:

They [non-specialist staff] are not working because they love their job. They just do their job [...] If you do it with love, that's different. I think that's the way with my midwife. She is doing it because she loves it and really they can't compare.

(Rachel)

The positive and trusting relationships built with HIV antenatal teams during pregnancy fostered confidence and encouraged many women to access antenatal care promptly during subsequent pregnancies.

Some women had referred themselves directly to the specialist midwife who had cared for them in a previous pregnancy, which provided a quick and direct way into the antenatal system. Women valued the close relationship they had fostered with their midwife, and often contacted them as soon as they realised they were pregnant. This underlines the strength of specialist midwives not only in terms of the skills that they bring to bear in their work but also the continuity of care they offer throughout pregnancy and sometimes across the course of a woman's reproductive trajectory. However specialist midwives sometimes felt that their skills were overlooked by other members of NHS staff. They described themselves as being poorly valued by colleagues in maternity services, often being pressurised to take on additional non-HIV related roles which took them away from their HIV work. The potential erosion of their specialist role, in the context of widespread cuts in public sector funding and over-stretched maternity services threatens to undermine the high standards of specialist antenatal care that HIV-positive women receive, potentially impacting upon women's willingness to engage early in the antenatal process.

7.3.2 Barriers to antenatal care access

Late booking was rarely discussed during my interviews[260], although HIV specialist midwives recognised late booking as a challenge and identified particular barriers to early booking for women living with HIV. One was women's fear that they may be judged for having had unprotected sexual intercourse. Another was fear of toxicity of ART to their unborn child and a desire to avoid medication in the critical first twelve weeks of foetal development. In a clinical setting where prevention of vertical transmission is paramount, women may not feel able to discuss their anxieties openly resulting in some women delaying access to care in an attempt to avoid judgement by healthcare professionals. This raises concerns that despite interpersonal relationships with healthcare professionals being defined by patients as positive and supportive, there exists an underlying power structure that may constrain some women's capacity to discuss their reproductive lives openly with healthcare providers.

Unplanned pregnancy was common among the women I interviewed with eighteen of the twenty-four describing their pregnancies as such. The two women who had presented late for antenatal care both described their pregnancies as unplanned and had not considered the possibility of pregnancy until second trimester. For one participant, this pregnancy had come within a year of delivering her first child after a single episode of unprotected sex, placing great financial strain on her and her partner. Her ambivalence towards her pregnancy resulted in her delaying seeking care until eighteen

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[260] This can be partly explained by the fact that national guidelines for antenatal booking evolved over the course of this study, with the shift towards booking between ten to twelve weeks occurring from 2010. There has been an inevitable a time lag between the publication of guidelines and the evolution of clinical practice.

weeks of pregnancy, explaining:

I liked to put it deep down in me because I knew I was going to get stressed.

(Audrey)

Both of the women who had booked late were attending HIV outpatient services prior to becoming pregnant, which is of particular concern as it suggests that their sexual and reproductive health needs may not have been addressed adequately.

However, these barriers do not explain why African women in particular were at greater risk of booking late antenatally. It is likely that this reflects ethnic inequalities in antenatal care booking more broadly in the general obstetric population. A recent study conducted at Newham University Hospital[261] found that almost 40% of pregnant women booked late for antenatal care beyond twelve weeks of pregnancy and that late booking was associated with non-white British ethnicity, inability to speak English and maternal birthplace outside the UK (Cresswell et al. 2013). Qualitative interviews undertaken in this study reveal that factors contributing to this disparity included poverty and differing notions of what kind of care is required during pregnancy (Professor Angela Harden, University of East London, personal communication, 28 Feb 2012). HIV antenatal care staff were conscious that their predominantly African clinic population may not subscribe to a biomedical view of pregnancy which may impact on their motivation to seek early antenatal care or may have culturally-defined reasons for delaying access to care[262]. However, it is important to exercise caution when ascribing delays in antenatal booking to inherently different conceptions of pregnancy. As discussed in Chapter Five, my participants had wide experience of biomedicine prior to migrating to the UK. Many had delivered children in hospitals in Africa, and clearly subscribed to a medicalised view of childbirth but early and regular attendance for antenatal care remains unusual throughout Sub-Saharan Africa (World Health Organisation 2006). Lack of adequate health infrastructure has precluded optimal antenatal care from becoming part of the ethno-obstetric system in many settings. Some African women may not be aware of the opportunity or benefits of booking early in pregnancy,

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[261] This study is of particular relevance to my work as it was conducted at one of my NHS fieldwork sites between 2008 and 2011.

[262] For example in their work in rural KwaZulu-Natal, Myer et al. describe how it is not is not deemed appropriate for a woman to seek care until she feels her baby move (2003). Moreover, disclosing pregnancy to anyone outside the immediate family in the early stages, when the baby is viewed as particularly vulnerable, may be seen as inviting supernatural misfortune as revealed by recent work on barriers to antenatal care in Africans in West London (Martha Chinyoua, University of Northumbria, personal communication, 17 July 2012).

regardless of HIV status. Late antenatal booking among African women living with HIV must therefore be placed in a wider context of disjunctures in obstetric healthscapes that manifest on migration. This contributes to a broader discussion of disjunctures in transnational healthscapes as experienced by HIV-positive African women in diaspora, which is highlighted by women's gratitude for access to ART in the context of global inequity in ART distribution as discussed in Chapter Five, and is developed further in Chapter Nine in discussions of global disparities in infant feeding advice.

7.4 Experiences on the labour ward[263]

During pregnancy, women living with HIV encounter many different parts of the NHS service, some of which are staffed by healthcare workers without expertise and specialist knowledge of HIV practice, attending appointments for foetal ultrasound scanning, blood tests, obstetric care, pharmacy and dentistry. The majority of women in this study described high standards of care antenatally. However, during their prenatal and postnatal interviews with me, some women reported isolated instances of sub-optimal treatment ranging from carelessness to overt discrimination. Some described inadvertent disclosure of their HIV status to family and friends. Others were concerned that their medical information was being passed between healthcare professionals without their consent, some of whom may not need to know their HIV status, compromising their ability to manage HIV-related information. A few women described being treated without kindness or consideration by staff who appeared busy, uninterested or judgemental, often attributing this to their HIV-status. Furthermore some had experienced overt discrimination including one who had been denied dentistry care after revealing her HIV status. Experiences of breaches of confidentiality and discrimination undermined some women's trust in the healthcare system, prompting them to consider concealing their HIV status should they go into labour and find themselves being looked after by staff they had not met before. This is of great concern, given that lack of disclosure may preclude important interventions during labour and postnatally to prevent vertical transmission.

Experiences of poor care within maternity services[264] were more common with eight of the fifteen women I spoke to postnatally describing poor treatment by staff.

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[263] The findings in this section are drawn entirely from interviews with my participants.

[264] I use "maternity services" to refer to the care women receive during labour and in the immediate post-partum period before being discharged home. This is in contradistinction to antenatal services, which for the purposes of this study have been considered separately.

Experiences of poor care ranged again from neglect to frank discrimination, and were especially painful at this critical juncture in a woman's journey to motherhood when she was likely to feel vulnerable and in need of support. Before I continue, I would like to present two vignettes from my fieldwork. My intention is not to romanticise these women's suffering but to highlight important failures within the NHS system. These vignettes provide an entry point into a wider discussion about poor maternity care experienced by African women living with HIV in the UK.

7.4.1 Rachel

Rachel, a 39-year-old Kenyan woman with French citizenship, had been diagnosed with HIV during her pregnancy on a routine antenatal screen. Towards the end of her pregnancy, Rachel began to struggle to pay her rent and was facing eviction. Despite being a French citizen and living in the UK for two years, she was not entitled to benefits as she had not been aware that she needed to register with the appropriate agencies. Her relationship with her controlling and verbally abusive partner had broken down during pregnancy and she received no support from him. Rachel told her midwife about her housing and financial difficulties, but did not want this to be shared with social services. However, social services were informed due to concerns about her child's welfare. They contacted Rachel four weeks before she was due to deliver, to inform her that they had no responsibility to care for her, only her baby. She was advised to return to France to deliver, or face the possibility that the child might be placed into foster care whilst they try and find her accommodation. During this time, Rachel felt under extreme pressure to return to France. Practically, she could not envisage making a long journey to the South of France (where she had friends) whilst being thirty-six weeks pregnant. However, she was frightened that her baby would be "taken" from her, convinced that this was part of a conspiracy to give her baby to a childless couple.

Rachel had made plans to travel to France at this late stage of pregnancy when she woke one day, at home on her own, with severe abdominal pain and bleeding. Unsure of who to contact at the hospital and frightened of further contact with services, she delayed seeking care until it was clear to her that things were going very badly wrong:

"I was breaking and my baby was breaking."

Finally she contacted a community midwife who informed her to dial 999 as she was too busy to come out to her. When the ambulance arrived a paramedic attempted cannulation several times, unsuccessfully. Rachel, in agonising pain and still without any treatment, begged to be taken to hospital but the paramedic team did not have a bed upon which to take her downstairs to the ambulance. Eventually she was carried downstairs, in great discomfort, by the paramedic team.

When Rachel finally arrived at hospital, nearly an hour and a half later, it was too late. She had suffered a placental abruption[265] and her baby was stillborn. Whilst recovering in hospital, she was visited several times by social workers who continued to discuss her case with her, seemingly oblivious to the recent devastating events. Some of these conversations took place in front of Rachel's visitors, resulting in inadvertent disclosure of her HIV status. When Rachel was discharged from hospital, she left with only £20 to buy food and advice to look for work as soon as possible. Her church stepped in to pay for her son's burial.

Rachel was clear that the pressure she had been put under during her pregnancy had resulted in her son's death:

"he didn't want to smell the dirtiness of this world and to feel the pollution and to see the wicked people, so he opened his eyes and then started to break".

7.4.2 Esther

Esther was in her mid-30s and had recently delivered her third child since being diagnosed with HIV in 2006. Originally from Ghana, she had been in the UK for eleven years and lived with her husband and children. Her pregnancy had been largely uneventful and she felt she was well prepared having been through the process twice before. However, this time her delivery had been a:

"horrible, horrible experience. Like a horrible movie; a horror movie."

Esther had planned to have a vaginal delivery so when she started getting contractions she went straight to her maternity unit. On arrival her cervix was found to be 8cm dilated and she was taken straight up to the delivery suite. Once there, she was informed that there were no midwives free and she was placed in a wheelchair in the main waiting area. Esther's contractions were becoming more and more frequent and

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[265] When the placenta becomes separated from the uterine wall, with considerable risk to mother and baby.

she was in considerable pain. She was also alone, as her husband had stayed at home to care for her other two children. Whilst waiting to be allocated a room, Esther was confronted by one of the midwives who put his hands to her face and asked her why she was shouting, chastising her for making so much noise. Exhausted and in pain, Esther burst into tears. After half an hour, she was given a room but offered no assistance in transferring from her chair to the bed.

Finally a midwife arrived. However Esther overheard her talking to a colleague outside describing her as *"high, high risk"*, seemingly with reference to her HIV, and expressing some reluctance to attend to her. The midwife was told by her colleague that she was obliged to continue regardless of Esther's "high risk" and reluctantly entered the delivery room. Esther's labour proceeded without complication. After giving birth, she was handed her baby by the midwife without him being bathed, something that had been specified in her birth plan. Furthermore, she was left alone in her soiled sheets and *"a pool of blood"*, her baby by her side. No one came to check up on her in the three hours she waited in the delivery room. She was only given clean bedding and assistance in washing when the new day shift brought a new midwife who was shocked at the condition she had been left in.

Esther described herself as having been *"dehumanised"* by events at the hospital that morning. She felt betrayed by the very people she had entrusted her care to. It had also stirred up similar emotions and anxieties to when she had first been diagnosed with HIV in 2006 and resulted in her feeling low after her son's birth. She eventually received a letter of apology from the NHS trust in response to a complaint and she was adamant that it would not stop her returning for HIV care at the same hospital. However, two months later, she was still clearly profoundly affected by her experience:

"when I think of the experience I just had…I wanted to have between four or five kids but when I came back I said to my husband 'no, this is the end of it'".

7.4.3 Failures in care

As demonstrated in both cases above, some women experience neglect in care within health services, especially maternity services, around the time of delivery. This neglect was far ranging and included delays in reaching hospital, limited pain relief, being left alone at critical points during and after labour, and not being treated with kindness and respect. Some women had noted that this had been different to previous experiences of maternity services in the UK, and attributed this to staff shortages, some pointing to the well-publicised health sector cuts. Many found it hard to ascertain whether their poor treatment was a direct result of their HIV-status or whether it reflected broader problems within British maternity services.

A recent study revealed an increase in maternal morbidity in London between 2005 and 2011 (Bewley et al. 2012), although the authors state that it is hard to know whether this was due to increasing complexity of cases or a decline in quality of services. There is currently a recognised deficit in the maternity services workforce in the UK, with a particular problem in staff retention in London, which has resulted in huge pressures within the system (Royal College of Midwives 2011) and fragmentation of services (Bourke 2013). A national review of maternity services across 152 NHS trusts identified significant problems with poor levels of staffing, lack of continuity of care and poor facilities (Healthcare Commission 2008). A survey of women's experiences of maternity care has shown a variability of services across the country. Two of the NHS trusts that I conducted fieldwork within received average scores for their maternity services at the time of my fieldwork, although one scored badly in the domain pertaining to women being treated with kindness and respect[266] (Care Quality Commission 2010). The other centre I was based in had been scored below average in all aspects of care during and after delivery, most notably in trust in staff, being left alone during and after labour, and communication between staff and patients. This same survey of 20,000 women in England identified that only 63% reported being treated with kindness in maternity services, whilst 8% reported not being able to obtain pain relief during labour.

It is therefore important to place HIV-positive women's experience of maternity services within a broader context of widespread difficulties in maternity care in general. There are also important ethnic disparities in care with studies showing that women from black and minority ethnic communities experience poorer levels of maternity care (Bharj et al. 2008)[267]. A qualitative study of maternity care in women from black and minority ethnic communities demonstrated that experiences of racism and ethnic stereotyping were not uncommon (McCourt et al. 2000). There has been very limited

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[266] Data obtained from Survey of Women's Experiences of Maternity Care available at http://www.cqc.org.uk/surveys/maternity, accessed 26 September 2013.

[267] Between 2006 and 2008, maternal morbidity and mortality was higher in black African women than white British women (Centre for Maternal and Child Enquiries 2011). Nineteen maternal deaths were reported in African-born women, the majority being in asylum seekers, refugees and new migrants. Again it is hard to establish whether this is due to poorer health within this group or poorer care.

qualitative research specifically into the experiences of maternity services within black African communities in the UK. However, two studies with Somali women in London have also highlighted the prevalence of racism and ethnic stereotyping, as well as identifying lack of appropriate interpreting services as an important barrier to receiving good care (Bulman et al. 2002, McLeish 2005).

Some of my participants certainly encountered worse care as a result of social marginalisation, highlighting how women come to embody structural inequalities in the form of suffering during labour recalling the earlier discussion of women's embodiment of structural violence in terms of access to ART in Chapter Five. Rachel had been aggressively pursued by social services in the latter stages of her pregnancy. Not only did she feel that this had contributed to her obstetric complications, but it also manifested in delays in her seeking care when things started to go wrong. She was further disempowered by the fact that her partner had abandoned her, expressing doubt that social services would have got involved had he financially supported her. Other women felt that their poor experience would have been avoided had they been accompanied by partners and friends who could have advocated on their behalf. Their social isolation, often a result of stigma or fear of it, had made them particularly vulnerable to poor levels of care. This echoes the work of both Martin (1987) and Jordan (1997) who have highlighted the central role of social networks in helping women in the US secure better standards of care and choice during labour. Being alone and from a socially marginalised group that may be perceived to be less likely to complain made many women especially vulnerable to abuses of care:

I think they treat you like dogs [...] they are treating lots of people who are afraid to talk about them.

(Rachel)

Of the eight women who experienced poor care within maternity services at the time of delivery, two described overt discrimination as a result of their HIV-status. Four others could not say for certain whether their experiences had been driven by stigma towards their HIV status, as this was often not made explicit by healthcare providers. However, they were sensitive to the possibility that it was a result of being HIV-positive. It is useful here to refer to the work of Scambler and Hopkins on stigma and epilepsy (1986) in which they make a distinction between *enacted* stigma, that is identifiable acts of discrimination, and *felt* stigma which is "more complex [and] refers principally to the fear of enacted stigma, but also encompasses a feeling of shame" (Ibid.: 33). Although, enacted stigma was not common, felt stigma was experienced by some participants resulting in anxiety and mistrust when entering maternity services.

However, some women such as Esther had experienced enacted stigma within maternity services as a direct result of their HIV status. Sandelowski's metasynthesis of work on stigma in HIV-positive women highlights the centrality of felt and enacted stigma in the lives of women living with HIV (2004). Studies have previously described discrimination towards HIV-positive women within maternity services, although this work is largely from the US or predates the HAART era (Prince et al. 1989, Green et al. 2000, Tyer-Viola 2007). A cross-sectional study of people living with HIV in East London found that almost one in ten women had experienced discrimination from healthcare providers within maternity services (Elford et al. 2008a) whilst recent work from Northern Ireland has revealed that HIV-related negative experiences of healthcare were commonly described by HIV-positive pregnant women (Kelly et al. 2012b).

I was particularly struck by Esther's story. It seemed highly symbolic that she be left in soiled sheets and her own "high risk" blood, with her baby unwashed. It appeared to be a remarkable dereliction of duty. On one level it is easy to partly attribute this type of behaviour as instrumental stigma, driven by a fear of HIV transmission in staff who have limited knowledge and experience of caring for those living with HIV. However, it is important to remember that stigma is created within a wider social context[268]. Collective representations of HIV have associated it with other discrediting attributes such as perceived sexual deviance and injecting drug use. This symbolic violence operates on a pervasive level and often operates unnoticed and unremarked upon[269]. Furthermore, there is a synergistic effect between HIV-related stigma and other forms of social inequality such as ethnicity and immigration status, which can constrain people's capacity to confront discrimination (Castro et al. 2005). Stigma produces and reproduces power relations, and acts to serve the interests of a dominant group. The use of stigmatising ethnic stereotypes within midwifery has previously been described (Bowler 1993). Not only does it function as 'shorthand' in midwives' decision-making about the type of care a patient requires, but it also protects against anxiety that may be

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[268] Here, I refer back to the summary of theoretical work on stigma and discrimination presented in Chapter One (36-37).

[269] Parker and Aggleton describe the notion of symbolic violence, with reference to Bourdieu, as it relates to HIV-related stigma (2003). It is the process by which "symbolic systems" operate to serve the interests of dominant groups through the mobilisation of cultural resources in daily practice to legitimise structures of inequality through hegemony in almost intangible ways.

evoked by patients that present challenges. I suggest that in this particular context some maternity care staff with little knowledge and experience of HIV may subconsciously employ negative stereotypes to serve their own interests in protecting themselves from anxiety.

But how does stigma and discrimination operate in the case of the HIV-positive *pregnant* woman? Much of what I have described thus far could apply to other services within healthcare. Whilst recognising the importance of instrumental stigma and fears surrounding HIV transmission, it is important to note that these fears are exaggerated in the context of women being on ART and the low risk of HIV acquisition through occupational exposure. So what else could be at play and what is it in particular about *pregnancy* and HIV that produces stigmatising attitudes? Using the work of the social anthropologist Mary Douglas ([2002] 1966) and the psychoanalytic theorist Julia Kristeva (1982), I wish to explore the symbolic processes that may lie beneath the interactions between maternity care providers and HIV-positive women[270].

Esther's experience in hospital suggests a deep-rooted fear of her "high-risk" blood manifesting in her midwife's reluctance to care for her, clean her sheets or bathe her baby. Esther's blood was seen as polluting. The notion of HIV as polluting was further reinforced by women's own internalised stigma highlighted by repeated references to their disease or themselves as "disgusting" or "dirty". Douglas ([2002] 1966), in her seminal work on pollution and taboo, laid bare the symbolic basis of pollution beliefs. For Douglas the body is a representation of the social order at large, with the integrity of the body mirroring the integrity of the body politic. Rules governing what constitutes bodily pollution and danger are therefore likely to symbolise deeper anxieties about threatened social structures. The creation of domains of the pure and the polluting is an inherently symbolic process, and represent an attempt to impose order on experience. If we set aside the instrumental reasons as to why HIV may be seen as polluting, we can try and engage with what other forces may be operating. Douglas writes:

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[270] Harris (2009) deploys a similar theoretical framework in her study of hepatitis C related stigma, exploring notions of breaching of bodily boundaries and symbolic ambiguity which I will be elaborating upon with reference to the HIV-positive labouring woman.

> “The body is a model which can stand for any bounded system. Its boundaries can represent any boundaries which are threatened or precarious.”
>
> (Douglas [2002] 1966: 142)

Bodily margins, like all margins, are dangerous as they stand at the border between one thing and another, constituting the most vulnerable part of what they attempt to contain. Green and Sobo (2000) note that fear of HIV-infection in healthcare workers through medical procedures was intensified if they involved “symbolically important areas […] such as the mouth and throat [and] the vagina” (Ibid.:127). The authors attribute this to their social salience and use in fundamental processes such as communication and sex. However, they are also structures at the margins, which may imbue them with symbolic notions of danger. The HIV-positive delivering woman is different to many other people living with HIV. Her boundaries have been breached through the physiology of pregnancy[271]. The woman herself may feel this in that the breaching of the boundaries between herself and her baby (the umbilical cord and the vaginal passage), become especially dangerous in the context of risk of vertical transmission.

When confronted with dirt and disorder, we have two actions open to us. We can either contain it, or we can reject it in an attempt to ward off danger (Yang et al. 2007). This realm of the rejected that instils disgust and horror is termed the *abject* by Kristeva (1982). Both Douglas and Kristeva see ambiguity at the heart of pollution and abjection respectively. Douglas describes the dangers of the person “in a marginalised state” whose status cannot be defined ([2002] 1966: 118). A prime example is the unborn child, not dead but not yet fully alive, who along with its pregnant mother is often viewed as dangerous in many cultures (Ibid.). Kristeva’s notion of abjection is similar:

> “It is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite.”
>
> (Kristeva 1982: 4)

I suggest that stigma towards HIV-positive pregnant women may arise as a combined product of the dangers inherent in the breaching of bodily margins, and their anomalous

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[271] See also Hausman’s work on HIV and breastfeeding where she argues that pregnant and lactating women are “special targets of risk discourses” because of the permeability of the maternal body and the lack of “rigid body boundaries” (2011: 127).

position in the symbolic order. HIV-positive pregnant women disrupt simple binary oppositions. They represent the idealised contained sexuality of the mother and the uncontained sexuality of people living with HIV, in dominant collective representations of HIV. They appear, on the whole, well but are unwell. They are the nurturing mother who has the potential to harm her child; the responsible mother and the irresponsible woman who risks bearing a child who may acquire HIV. They embody life and death; joy and sorrow. Furthermore, they are not quite separate enough. Kristeva writes that the abject "lies there, quite close, but… cannot be assimilated" (Ibid.: 1). The HIV-positive mother does not fully occupy the position of *other* and is not quite "different enough" (Harris 2009: 41). It is the combined power of ambiguity and recognition of self that invites abjection; a strategy that restores symbolic order by placing HIV-positive mothers in the realm of the abject.

In a study in 1992 Green and Sobo discovered that one of their participants had been "forced to sleep in sheets 'all covered in blood' after she gave birth" (2000: 125). It seems remarkable that twenty years later I would be told similar stories. However, a symbolic account of stigma, rather than a functional one, can help us understand the durability of these responses. Childbirth can be a time when a woman feels especially vulnerable, and these experiences coming at this critical juncture in women's transition into motherhood had considerable impact with many women crying as they spoke of what had happened to them. These abuses within healthcare, whether frank discrimination or interactions that lack empathy and kindness, often remain invisible yet cause considerable suffering, violating the trust women have in healthcare professionals and risking future engagement with services. For my participants perceived stigma from healthcare professionals, a group which has the status of "wise" (Goffman [1990] 1963)[272], reified internalised notions of shame about their HIV-status and served to constrain women's future reproductive decisions and their long-term engagement with healthcare services as a whole. Healthcare professionals are, with good reason, expected to be informed about conditions such as HIV and to act with compassion and without judgement (Green et al. 2000: 132). Given the position of power they occupy, their discriminatory behaviour may be especially corrosive.

Despite these painful stories, none of the women who had disclosed receiving poor maternity care said that this would deter them from coming back for HIV care

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[272] Goffman describes the "wise" as people who are do not have the discrediting attribute but have specialist knowledge or experience of working with the stigmatised.

postnatally; all of them seeing the HIV clinic as being completely separate from the maternity services.

7.5 Conclusions

In this chapter I have used a combination of national surveillance and ethnographic data to explore how women access and experience health services during pregnancy. Nearly 50% of women diagnosed with HIV do not present to antenatal care until beyond thirteen weeks of pregnancy, with African women being at higher risk of late booking than white British women. This does not appear to be HIV-related *per se*, but rather a reflection of broader ethnic disparities in antenatal care access in general. Unplanned pregnancy, cultural constructions of pregnancy, lack of knowledge of the importance of early booking and the effects of structural inequalities such as poverty and insecure immigration status, may also be important contributing factors.

Once booked the majority of women describe good care within HIV antenatal services forging good relationships with healthcare providers. However, some women described experiences of poor care within maternity services, which was more pronounced at the time of delivery. This ranged from neglect, perhaps reflecting wider constraints within maternity services in general, to overt discrimination as a result of their HIV-positive status. I have attempted to move beyond the instrumental nature of stigma through an exploration of deeper symbolic processes such as the breaching of bodily integrity and the notion of abjection in order to explain the persistence of stigma towards HIV among healthcare professionals in a post-HAART era.

Key points

- One in two HIV-positive women in the UK booked late for antenatal care between 2008 and 2010, with African women more likely to book late.

- Late antenatal booking in HIV-positive African women is likely to reflect broader ethnic disparities in antenatal access in the UK due to a number of factors including poverty, lack of knowledge of services and cultural constructions of pregnancy.

- The majority of women described positive experiences of HIV antenatal care.

- Some women described poor care within maternity services, particularly around the time of delivery, ranging from neglect to overt discrimination.

8

Returning to HIV services after pregnancy

Summary

In this chapter I explore the engagement with HIV services by African women for their own care *after* pregnancy. In this third and final mixed methods empirical chapter of the thesis, I first use NSHPC data to examine the association between loss to follow-up from HIV care in the year after pregnancy and: (i) maternal ethnicity, (ii) maternal African region of birth, and (iii) maternal duration of residence in the UK at conception. I then contextualise these findings with ethnographic data to explore what facilitates engagement with HIV care after pregnancy, and why some women may find it hard to engage.

8.1 Introduction

In the previous chapter I explored the engagement with and experiences of health services *during* pregnancy. I found that one in two HIV-positive women booked late for antenatal care, with African women more likely to book late than their white British counterparts. However, once engaged in care most women described positive experiences with their HIV antenatal care team. In contrast, a number of women described negative experiences of care within maternity services around the time of delivery, perhaps as a result of their HIV-positive status.

HIV clinical care does not conclude with the end of pregnancy. HIV is a chronic, if manageable, condition requiring long-term engagement with clinical services in order to access monitoring and treatment, if indicated. It is important that women attend specialist HIV services after pregnancy to safeguard their own health, which also has a consequent effect on their dependent children and their risk of transmitting HIV sexually. The transformation of HIV into a chronic condition has resulted in retention in care becoming a priority in the delivery of HIV services with recent UK standards recommending that ≥95% of people diagnosed with HIV should be accessing clinical services at least once a year (British HIV Association 2012). Factors such as poor experiences of maternity care and the responsibilities of looking after a baby may make it particularly difficult for a woman to access healthcare after pregnancy. However, as discussed in Chapter Two, very little is currently known about the access to HIV services by women after pregnancy, especially within resource-rich settings such as the UK.

In this final mixed methods empirical chapter of the thesis, I focus upon women's engagement with HIV services *after* pregnancy. First I use data from the NSHPC to examine the relationship between maternal ethnicity, African region of birth and duration of residence in the UK, and loss to follow-up from HIV care in the year after pregnancy. I then contextualise these findings with ethnographic data, based mainly on interviews with pregnant women and their healthcare providers in order to explore women's engagement with HIV services after pregnancy and possible barriers to accessing care.

8.2 Epidemiological data on maternal loss to follow-up after pregnancy

In this section I explore the association between loss to follow-up from HIV care in the year after pregnancy and: (i) maternal ethnicity, (ii) maternal African region of birth, and (iii) maternal duration of residence in the UK at conception (for African women).

This analysis was restricted to pregnancies reported to the NSHPC with an EDD (if the outcome was not a live or still birth) or actual date of birth between January 2000 and December 2009. Pregnancies or attendances reported in Scotland were excluded from this analysis. Up until recently, reports from Scotland were not linked over time and it was therefore not possible to track the same patient over time reliably. Pregnancies were also excluded if it was documented that the woman had left the UK during her pregnancy[273]. Year of EDD or date of delivery was included in all models as an a priori confounder. Other potential confounders considered included maternal age, history of injecting drug use, time since diagnosis, last CD4 count and viral load in pregnancy, reporting region, outcome of pregnancy and gestation at delivery. Robust standard errors were used to account for possible clustered effects in sequential pregnancies in the same mother. This analysis is based on a matched dataset using data from the

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[273] Only a small proportion (17.2%, 27/157) of women who were reported to have left the UK during their pregnancy appeared in subsequent SOPHID or NHSPC datasets and it was therefore reasonable to assume that if a woman left the country that she did not return.

NSHPC and the Survey of Prevalent HIV Infections Diagnosed (SOPHID)[274]. Loss to follow up (LTFU) was defined as no documented attendance for HIV care at a NHS clinic in England, Wales or Northern Ireland during the calendar year after the end of pregnancy[275]. This measure was selected as a result of new draft standards of HIV care by the British HIV Association (British HIV Association 2012) that defines loss to follow-up as not accessing clinical services for twelve months[276]. For the purposes of this study LTFU was categorised as "No" or "Yes". It is likely that some women who were reported to the NSHPC as pregnant were not matched in SOPHID because they had never attended for HIV care in England, Wales or Northern Ireland. There is a therefore a possibility of underestimating LTFU if these pregnancies are excluded. To address this, two multivariable logistic regression models were built for each exposure variable. In model 1 pregnancies in women that were not matched on the SOPHID dataset were excluded from analysis. In model 2 women who were not matched in the matching process were assumed to be lost to follow-up and coded as such.

8.2.1 Results

There were 8150 eligible pregnancies reported to the NSHPC between January 2000 and December 2009, of which 7219 (88.6%) were in women who were matched with records in the SOPHID database.

Eight pregnancies were in women who were known to have died in either the year of pregnancy or the year after, and they were excluded from analysis. This analysis is therefore based on 7211 pregnancies in 5390 women. Like previous analyses, nearly 90% of pregnancies (6485/7211) were in African women. Other demographic and clinical characteristics of the study population are presented in table 8.1.

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[274] See Chapter Three for an overview of SOPHID and a description of the record linkage process (63-65).

[275] There is no standardised definition for loss to follow-up in HIV with numerous measurements used in studies such as varying lengths of time between outpatient appointments (Yehia, et al. 2012, Chi, et al. 2011, Helleberg, et al. 2012).

[276] It also allows comparison with previous studies on loss to follow-up in the overall HIV-positive population in the UK (Rice et al. 2011).

Table 8.1: Demographic and clinical characteristics of women with pregnancies reported to the NHSPC in 2000-2009 by maternal follow-up in the calendar year following pregnancy

	Not LTFU by 1 year, n (row %) n=6309	LTFU by 1 year, n (row %) n=902	*p*-value*
Ethnicity, n=7211			
White British	669 (92.2)	57 (7.9)	<0.001
African	5640 (87.0)	845 (13.0)	
Maternal age at delivery, n=7060			
<25 years	808 (83.3)	162 (16.7)	<0.001
25-34 years	3853 (87.9)	530 (12.1)	
≥35 years	1556 (91.2)	151 (8.9)	
Year of EDD/delivery, n=7211			
2000-2003	1487 (86.2)	238 (13.8)	0.003
2004-2006	2188 (86.5)	341 (13.5)	
2007-2009	2634 (89.1)	323 (10.9)	
IDU, n=7211			
No	6271 (87.5)	900 (12.6)	0.150
Yes	38 (95.0)	2 (5.0)	
Last CD4 count¶, cells/µl, n=6223			
≥350	3339 (87.5)	478 (12.5)	<0.001
200-249	1544 (90.6)	161 (9.4)	
<200	639 (91.2)	62 (8.8)	
Last HIV viral load¶, copies/ml, n=6297			
<50	3632 (90.9)	366 (9.2)	<0.001
≥50	1944 (84.6)	355 (15.4)	
Time since HIV diagnosis, n=6594			
>5 years	1199 (93.4)	85 (6.6)	<0.001
1-5 years	2100 (89.2)	254 (10.8)	
<1 years	2510 (84.9)	446 (15.1)	
Reporting region, n=6480			
London	3043 (89.3)	363 (10.7)	0.001
England (not London)	2564 (86.2)	410 (13.8)	
Wales and Northern Ireland	90 (90.0)	10 (10.0)	
Outcome of pregnancy, n= 7060			
Live birth	5610 (87.9)	769 (12.1)	0.594
Still birth	65 (86.7)	10 (13.3)	
Miscarriage/ectopic	333 (90.2)	36 (9.8)	
Termination	209 (88.2)	28 (11.9)	
Gestation at delivery¶¶, n=6416			
≥37 weeks	4833 (87.9)	666 (12.1)	0.634
<37 weeks	811 (88.4)	106 (11.6)	

* Obtained using χ^2 test. ¶ Last reported value in pregnancy. ¶¶ Restricted to live and still births. EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use.

Overall, in 12.5% of pregnancies reported to the NSHPC women did not access HIV care in the year after pregnancy (902/7211; 95% CI: 11.7%, 13.3%)[277]. This proportion rose to 22.5% (1833/6309; 95% CI: 21.6%, 23.4%) when unmatched records were included and coded as lost to follow-up. Therefore the proportion of pregnancies where women were lost to follow-up in the subsequent year was likely to be between 12.5% and 22.5%.

On univariable analysis there was an association between LTFU and ethnicity, younger maternal age at delivery, earlier year of EDD/delivery, higher maternal CD4 count at the end of pregnancy, detectable maternal viral load at the end of pregnancy, more recent maternal HIV diagnosis and pregnancy being reported in areas of England outside London (all $p<0.05$; table 8.1). There was no association between either injecting drug use as the route of HIV acquisition or outcome of pregnancy and LTFU ($p>0.1$).

The percentage of LTFU varied over time rising from 9.0% in 2000 to a peak of 15.1% in 2003, falling to 11.1% in 2009 ($p<0.05$; figure 8.1). Of the 902 women who did not return for HIV care in the year after pregnancy, 22.2% returned in the subsequent year. After excluding women who died during the study period, a total of 460 women who had been reported as pregnant to the NSHPC (6.4%; 95% CI: 5.8%, 6.9%) never returned for follow-up by the end of 2010.

The proportion of women who returned for follow-up after pregnancy by the end of the study period (December 2010) decreased between 2000 and 2009 (χ^2_{trend} test $p<0.001$; figure 8.2). However, this was mainly due to the fact that women who were pregnant earlier in the study period had greater opportunity to return for care by December 2010 than those in later years. To obtain a more accurate estimate, I looked at the proportion of pregnancies after which women did not return for HIV care in the five years after pregnancy, restricting this to pregnancies reported between 2000 and 2005. Nearly 6% of women who were reported as pregnant between 2000 and 2005 did not return for HIV care in the five years after their pregnancy, excluding 28 women who died during this time period (183/3309; 5.5%; 95% CI: 4.8%, 6.3%). The proportion lost to follow-up at five years did not vary over time ($p>0.1$). Loss to follow-up at five years was more common in women of African ethnicity than of white British ethnicity (6.1% *vs.*

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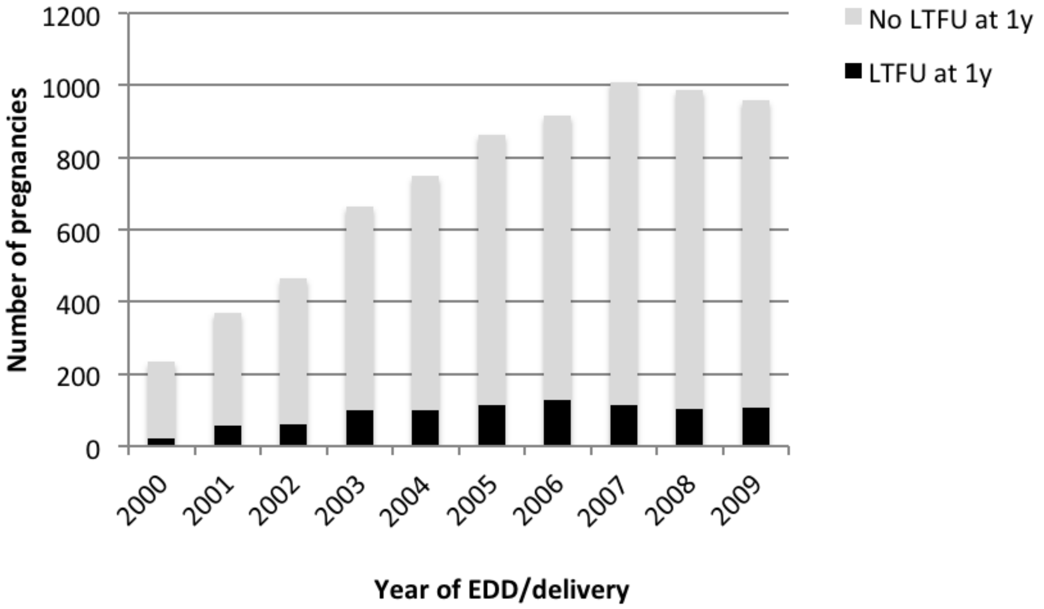
[277] Some of these pregnancies were in sequential pregnancies in the same woman. These were included in the analysis as independent observations with robust standard errors to account for clustering.

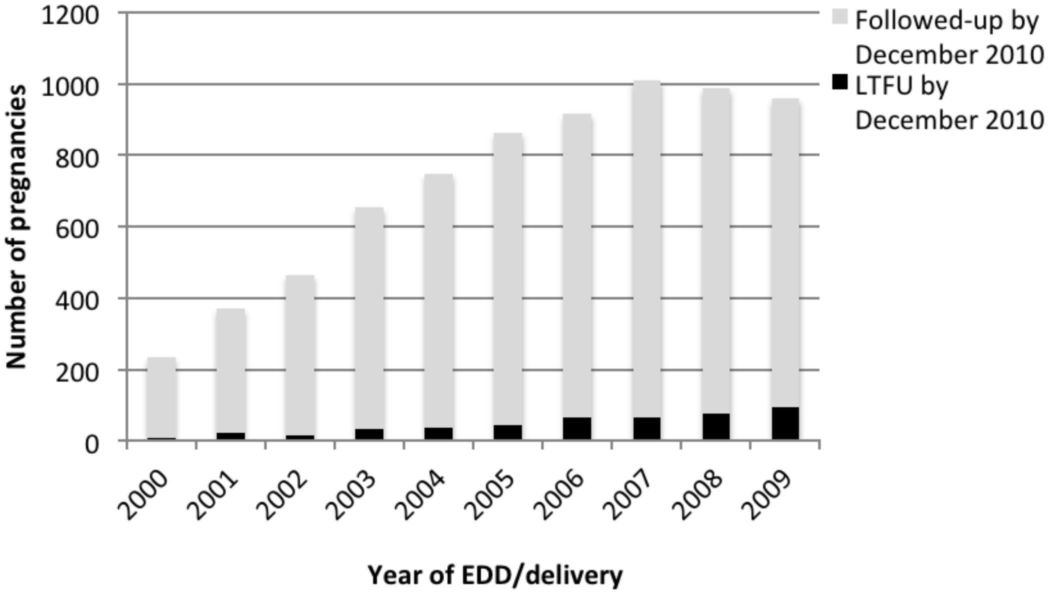
1.2%; *p*<0.001). Among African women, a greater proportion of those from Western and Southern Africa and those who had arrived in the UK during conception did not return for HIV care in the 5 years following their pregnancy (all *p*<0.001).

Figure 8.1: Trends over time in loss to follow-up in the calendar year following pregnancy, 2000-2009



LTFU, loss to follow-up; EDD, estimated date of delivery

Figure 8.2: Trends over time in loss to follow-up to December 2010



LTFU, loss to follow-up; EDD, estimated date of delivery

Returning to loss to follow-up in the year after pregnancy, a greater proportion of African women (13.0%; 845/6485) were lost to follow-up compared with women of white British ethnicity (7.9%; 57/726; *p*<0.001). After adjusting for maternal age, year, last CD4 and viral load in pregnancy, time since HIV diagnosis and reporting area, African women were twice as likely as white British women to be lost to follow-up in the year subsequent to their pregnancy (AOR 2.17; 95% CI: 1.50, 3.14; *p*<0.001; table 8.2, model 1). This association persisted but was attenuated when I included women who had not been matched in the matching process (AOR 1.65; 95% CI: 1.27, 2.16; *p*<0.001; table 8.2, model 2).

Restricting the analysis to pregnancies in African women, a significantly higher proportion of Southern African women (22.1%; 105/476) and Western African women (16.0%; 227/1415) did not return for HIV care in the year after pregnancy compared with women from Eastern Africa (11.0%; 432/3919) and Middle Africa (12.0%; 81/675; *p*<0.001). After adjusting for maternal age, year, last CD4 and viral load in pregnancy, time since HIV diagnosis and reporting area, Southern African women were twice as likely as Eastern African women not to return for HIV care in the year after pregnancy (AOR 1.99; 95% CI: 1.48, 2.67; *p*<0.001; table 8.3, model 1). Western African women also had increased odds of being lost to follow-up in the year after pregnancy compared with Eastern African women (AOR 1.56; 95% CI: 1.25, 1.56; *p*<0.001; table 8.3, model 1). These associations were attenuated but remained significant when women who were not matched were included and coded as lost to follow-up (table 8.3, model 2).

Among African women there was a difference in LTFU according to maternal duration of residence in the UK at conception. A greater proportion of women who arrived in the UK after conception (23.9%; 76/318) and those who arrived less than four years prior to conception (13.2%; 246/1866) did not return for HIV care in the year after pregnancy compared with women who had resided in the UK for four or more years prior to conception (9.7%; 213/2203; *p*<0.001). After adjusting for year, last CD4 and viral load in pregnancy, time since HIV diagnosis and reporting area, the odds of not returning to care in the year after pregnancy were similar for women who had arrived in the UK less than four years prior compared with those who had been in the UK for four or more years (AOR 1.11; 95% CI: 0.86, 1.44; *p*>0.1; table 8.4, model 1). This remained the case when unmatched women were included in the analysis and coded as lost to follow-up (table 8.4, model 1). However, women who had arrived in the UK *after* conception were over 1.5 times more likely to be lost to follow-up during the year after pregnancy compared with those who had been in the UK for four or more years (AOR 1.60; 95% CI: 1.06, 2.42; $p<0.05$; table 8.4, model 1). Again, the results were similar when women who were not matched across the datasets were included in the analysis (table 8.4, model 2).

Table 8.2: Univariable and multivariable analysis of the association between maternal ethnicity and loss to follow-up in the calendar year following pregnancy

	Univariable analysis		Model 1 Multivariable analysis, n=5741		Model 2 Multivariable analysis, n=6042	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Ethnicity						
White British	1.00		1.00		1.00	
African	1.76 (1.34,2.33)	<0.001	2.17 (1.50,3.14)	<0.001	1.65 (1.27,2.16)	<0.001
Maternal age at delivery						
<25 years	1.00	<0.001	1.00		1.00	
25-34 years	0.69 (0.57,0.83)		0.73 (0.58,0.92)	0.009	0.76 (0.63,0.92)	0.005
≥35 years	0.48 (0.38,0.61)		0.67 (0.50,0.91)	0.009	0.82 (0.65,1.03)	0.086
Year of EDD/delivery						
2000-2003	1.00	0.003	1.00		1.00	
2004-2006	0.97 (0.81,1.16)		1.04 (0.82,1.31)	0.743	0.91 (0.76,1.08)	0.288
2007-2009	0.77 (0.64,0.92)		0.97 (0.76,1.24)	0.820	0.87 (0.72,1.04)	0.133
IDU						
No	1.00	0.107				
Yes	0.37 (0.09,1.52)					
Last CD4 count[¶], cells/µl,						
≥350	1.00	<0.001	1.00		1.00	
200-249	0.73 (0.60,0.88)		0.69 (0.56,0.84)	<0.001	0.84 (0.72,0.97)	0.020
<200	0.68 (0.51,0.89)		0.50 (0.36,0.70)	<0.001	0.67 (0.53,0.84)	0.001
Last HIV viral load[¶], copies/ml						
<50	1.00	<0.001	1.00		1.00	
≥50	1.81 (1.55,2.12)		1.78 (1.47,2.16)	<0.001	1.42 (1.23,1.64)	<0.001

Table 8.2 continued

	Univariable analysis		Model 1 Multivariable analysis, n=5741		Model 2 Multivariable analysis, n=6042	
	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Time since HIV diagnosis						
>5 years	1.00		1.00		1.00	
1-5 years	1.71 (1.32,2.20)	<0.001	1.54 (1.13,2.09)	0.006	1.58 (1.26,1.97)	<0.001
<1 years	2.51 (1.97,3.19)		1.95 (1.43,2.67)	<0.001	1.98 (1.58,2.49)	<0.001
Reporting region						
London	1.00	0.001	1.00		1.00	
England (not London)	1.34 (1.15,1.56)		1.29 (0.36,0.70)	0.007	1.47 (1.28,1.70)	<0.001
Wales and Northern Ireland	0.93 (0.48,1.81)		1.28 (0.59,2.74)	0.532	1.89 (1.16,3.09)	0.010
Outcome of pregnancy						
Live birth	1.00	0.575				
Still birth	1.12 (0.57,2.19)					
Miscarriage/ectopic	0.79 (0.55,1.12)					
Termination	0.98 (0.65,1.46)					
Gestation at delivery						
≥37 weeks	1.00	0.634				
<37 weeks	0.95 (0.76,1.18)					

Model 1: Analysis includes only records that were matched in NSHPC and SOPHID datasets.

Model 2: Pregnancies that were unmatched in SOPHID were recoded as lost to follow up.

¶ Last reported test in pregnancy. OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use.

Table 8.3: Univariable and multivariable analysis of the association between maternal African region of birth and loss to follow-up in the calendar year following pregnancy (restricted to African women)

	Univariable analysis		Model 1 Multivariable analysis, n=4933		Model 2 Multivariable analysis, n=5450	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
African region of birth						
Eastern Africa	1.00		1.00		1.00	
Southern Africa	2.28 (1.80,2.90)	<0.001	1.99 (1.48,2.67)	<0.001	1.60 (1.26,2.02)	<0.001
Western Africa	1.54 (1.30,1.83)	<0.001	1.56 (1.25,1.96)	<0.001	1.22 (1.02,1.47)	0.032
Middle Africa	1.10 (0.85,1.42)	0.457	1.04 (0.74,1.47)	0.824	0.85 (0.65,1.11)	0.234
Maternal age at delivery						
<25 years	1.00	<0.001	1.00		1.00	
25-34 years	0.64 (0.52,0.78)		0.74 (0.57,0.95)	0.020	0.72 (0.59,0.89)	0.002
≥35 years	0.45 (0.35,0.58)		0.71 (0.52,0.98)	0.036	0.81 (0.64,1.03)	0.092
Year of EDD/delivery						
2000-2003	1.00	0.003	1.00		1.00	
2004-2006	0.97 (0.80,1.16)		0.98 (0.77,1.25)	0.878	0.88 (0.73,1.06)	0.194
2007-2009	0.76 (0.63,0.91)		0.90 (0.70,1.17)	0.435	0.83 (0.68,1.00)	0.053
Last CD4 count[¶], cells/µl,						
≥350	1.00	<0.001	1.00		1.00	
200-249	0.73 (0.60,0.89)		0.72 (0.58,0.88)	0.002	0.83 (0.71,0.97)	0.018
<200	0.66 (0.50,0.88)		0.51 (0.37,0.72)	<0.001	0.66 (0.52,0.83)	0.001
Last HIV viral load[¶], copies/ml						
<50	1.00	<0.001	1.00		1.00	
≥50	1.85 (1.57,2.17)		1.86 (1.53,2.27)	<0.001	1.44 (1.24,1.68)	<0.001

Table 8.3 continued

	Univariable analysis		Model 1 Multivariable analysis, n=4933		Model 2 Multivariable analysis, n=5450	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Time since HIV diagnosis						
>5 years	1.00	<0.001	1.00		1.00	
1-5 years	1.70 (1.30,2.23)		1.55 (1.12,2.14)	0.009	1.65 (1.29,2.09)	<0.001
<1 years	2.48 (1.93,3.20)		1.80 (1.29,2.52)	0.001	2.00 (1.56,2.56)	<0.001
Reporting region						
London	1.00	<0.001	1.00		1.00	
England (not London)	1.42 (1.22,1.66)		1.40 (1.15,1.70)	0.001	1.53 (1.31,1.78)	<0.001
Wales and Northern Ireland	1.18 (0.53,2.62)		1.59 (0.70,3.62)	0.268	2.28 (1.29,4.04)	0.005
Outcome of pregnancy						
Live birth	1.00	0.392				
Still birth	1.20 (0.61,2.37)					
Miscarriage/ectopic	0.74 (0.51,1.08)					
Termination	1.03 (0.69,1.54)					
Gestation at delivery						
≥37 weeks	1.00	0.786				
<37 weeks	1.03 (0.82,1.29)					

Model 1: Analysis includes only records that were matched in NSHPC and SOPHID datasets.

Model 2: Pregnancies that were unmatched in SOPHID were recoded as lost to follow up.

[¶] Last reported test in pregnancy. OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use.

Table 8.4: Univariable and multivariable analysis of the association between maternal duration of residence in the UK at conception and loss to follow-up in the calendar year following pregnancy (restricted to African women)

	Univariable analysis		Model 1 Multivariable analysis, n=3507		Model 2 Multivariable analysis, n=3829	
	OR (95% CI)	*p*-value	AOR (95% CI)	*p*-value	AOR (95% CI)	*p*-value
Duration of residence in UK						
≥ 4 years	1.00		1.00		1.00	
< 4 years (before conception)	1.42 (1.17,1.72)	<0.001	1.11 (0.86,1.44)	0.425	1.16 (0.95,1.42)	0.150
Since conception	2.93 (2.19,3.94)	<0.001	1.60 (1.06,2.42)	0.026	1.65 (1.20,2.29)	0.002
Maternal age at delivery						
<25 years	1.00	<0.001				
25-34 years	0.69 (0.53,0.89)					
≥35 years	0.51 (0.38,0.71)					
Year of EDD/delivery						
2000-2003	1.00	0.078	1.00		1.00	
2004-2006	0.92 (0.73,1.16)		1.03 (0.76,1.39)	0.856	0.94 (0.75,1.19)	0.617
2007-2009	0.78 (0.62,0.98)		1.03 (0.75,1.42)	0.843	0.93 (0.73,1.19)	0.566
Last CD4 count¶, cells/µl,						
≥350	1.00	<0.001	1.00		1.00	
200-249	0.68 (0.54,0.86)		0.65 (0.50,0.83)	0.001	0.79 (0.65,0.96)	0.016
<200	0.58 (0.40,0.83)		0.39 (0.25,0.60)	<0.001	0.55 (0.41,0.75)	<0.001
Last HIV viral load¶, copies/ml						
<50	1.00	<0.001	1.00		1.00	
≥50	1.80 (1.48,2.20)		1.88 (1.48,2.40)	<0.001	1.44 (1.20,1.73)	<0.001

Table 8.4 continued

	Univariable analysis		Model 1 Multivariable analysis, n=3507		Model 2 Multivariable analysis, n=3829	
	OR (95% CI)	***p*-value**	**AOR (95% CI)**	***p*-value**	**AOR (95% CI)**	***p*-value**
Time since HIV diagnosis						
>5 years	1.00	<0.001	1.00		1.00	
1-5 years	1.75 (1.26,2.42)		1.67 (1.14,2.46)	0.009	1.78 (1.31,2.40)	<0.001
<1 years	2.58 (1.90,3.52)		1.93 (1.29,2.87)	0.001	2.16 (1.59,2.95)	<0.001
Reporting region						
London	1.00	<0.001	1.00		1.00	
England (not London)	1.50 (1.24,1.83)		1.35 (1.07,1.70)	0.012	1.45 (1.21,1.74)	<0.001
Wales and Northern Ireland	2.45 (0.98,6.09)		2.93 (1.15,7.46)	0.025	2.47 (1.16,5.24)	0.019
Outcome of pregnancy						
Live birth	1.00	0.348				
Still birth	0.78 (0.28,2.20)					
Miscarriage/ectopic	0.67 (0.41,1.09)					
Termination	0.86 (0.50,1.48)					
Gestation at delivery						
≥37 weeks	1.00	0.878				
<37 weeks	0.97 (0.73,1.31)					

Model 1: Analysis includes only records that were matched in NSHPC and SOPHID datasets.
Model 2: Pregnancies that were unmatched in SOPHID were recoded as lost to follow up.
¶ Last reported test in pregnancy. OR, odds ratio; AOR, adjusted odds ratio: EDD, expected date of delivery; IDU, likely route of HIV acquisition was maternal injecting drug use.

8.2.2 Summary of epidemiological analysis on maternal loss to follow-up after pregnancy

In this analysis I have shown that 12.5% of women do not return for HIV care in the year after their pregnancy. This is consistent with data in the general HIV-positive population in the UK (Rice at al. 2011). African women were more likely than white British women *not* to attend for HIV care in the year after pregnancy in keeping with documented associations between Black African ethnicity and retention in care in UK studies of loss to follow-up in the HIV-positive population overall (Gerver et al. 2010, Rice et al. 2011, Clay 2013)[278]. Looking at African women in more detail, women from Western and Southern Africa were at greater risk of being lost to follow-up than those from Eastern Africa, as were women who had arrived in the UK after conception. This will be explored in greater detail in the following section using ethnographic data.

The limitations of the dataset linkage between NSHPC and SOPHID and associations with non-matching are discussed in detail in Chapter Three. Another important limitation of this analysis is in the interpretation of loss to follow-up among those who were matched. We have no data on emigration, which may be an important reason for non-attendance for care[279]. Deaths are almost certainly under-reported to SOPHID, however they are likely to be few in number and not a major contributory factor. It is unlikely that patients would be seeking care in significant numbers within the private sector (Kupek et al. 1999) and it is therefore reasonable to assume that another explanatory factor in loss to follow-up is patient withdrawal from care.

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[278] It also fits with findings from other parts of Europe and the US showing poorer retention in care for patients of non-white ethnicity (Hall, et al. 2012, Rebeiro, et al. 2013 ibid, Helleberg, et al, Thierfelder, et al. 2012, Fleishman, et al. 2012a).

[279] A recent audit of adults in England, Wales and Northern Ireland with diagnosed HIV found that of 2255 patients who did not access care in 2011, one in four had left the UK (Clay 2013).

8.3 Ethnographic data on loss to follow-up after pregnancy

Discussions with clinical colleagues coupled with my own experiences of working in clinics with HIV-positive women, led me to initially question how effective HIV antenatal care is at fostering longer term engagement with HIV care:

The antenatal clinic is a very important front door for us for people to come through.

(Helen, HIV physician)

It has almost become received wisdom amongst clinicians that despite engaging women well in HIV care during pregnancy, it is not unusual for women to disappear after delivery, not to be seen in clinic again until they become pregnant again. However this is not borne out by the quantitative findings presented in this chapter. Although the 12.5% loss to follow-up rate presented in the previous section is higher than the ≤5% attrition at one year recommended in the British HIV Association's standards of care (2012), the key finding is that the majority of women *do* return for HIV care after their pregnancy.

The quantitative data reveal disparities in loss to follow-up after pregnancy according to ethnicity, African region of birth and duration of residence in the UK. African women, especially those from Southern and Western Africa and those who had arrived in the UK after conception, were more likely than white British women not to return to HIV care in the year after pregnancy. One key explanatory factor is emigration but this information is unavailable in both the NSHPC and SOPHID datasets. This is likely to contribute to the observed attrition post-pregnancy of women from Southern Africa due to the fact that South Africans are more commonly economic migrants as opposed to political asylum seekers and consequently may be more likely to be involved in circular migration between the UK and Africa (Owen 2009). However, it is unlikely that emigration is the sole reason for some women failing to return for HIV care after pregnancy. In this final section of this chapter I draw upon ethnographic data to explore access to HIV care after pregnancy. I will pay particular attention to why African women (especially those from certain regions and those who have most recently arrived in the UK) are at greatest risk of defaulting from care, and what can be done to facilitate their return to HIV care after pregnancy.

8.3.1 Coming back

Firstly, it is important to reiterate that the majority of women do return for HIV care in the year after their pregnancy. Out of the twenty-three women I interviewed in NHS clinics, I knew of seventeen that had returned to their clinic within three months of delivering their baby[280]. The primary motivation for continuing to engage in HIV care beyond pregnancy was the safeguarding of their health. The majority of women described their HIV infection in biomedical terms, explaining the importance of maintaining a good CD4 count. I was struck by how often the spectre of death hovered over conversations with pregnant women and new mothers. Many had lost friends and family to HIV-related illness, and feared the same fate despite having access to treatment in the UK. Some had been diagnosed with HIV many years ago in an era when their life expectancy was limited, and may not have been aware of the improvements in prognosis with current ART. Their uncertainties about survival were amplified by pregnancy and motherhood which, for many women like Grace, prompted rumination about their children's futures:

I just pray to God that he gives me a long life to take care of my children. Sometimes I am scared that I'm going to maybe die and leave my children. That's what I think.

The combination of fear of progression of disease and a biomedical conception of HIV was an important catalyst in the return of many women to HIV care postnatally. Women were keen to be monitored regularly by their clinical teams, through both medical consultations and routine blood tests. Through this regular surveillance, women were able to keep informed about their clinical condition, restoring a degree of control over their HIV. However rather than this "medical gaze" representing an exercise in biopower (Foucault [2003] 1963), engagement with HIV services and clinical monitoring were important resources for those living with HIV in the UK in confronting and managing anxieties about their and their families' future survival. For women who remained on ART after pregnancy for their own health, clinic attendance carried even more weight as it provided access to life-preserving medication. Attending for care gave women emotional reassurance about their future, making them feel "safe" and allowing them the opportunity to fulfil their ambition to be mothers without the

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[280] I interviewed fifteen women postnatally and was able to ascertain that they had returned for HIV care after delivery. I spoke to a further two women who did not wish to be interviewed again but stated that they had returned for care. I was unable to contact the remaining six women postnatally and therefore could not determine if they had returned to HIV services after their pregnancy.

pervasive fear that their children would grow up without them. Engaging with HIV follow-up postnatally therefore serves a similar function to the use of ART during pregnancy as described in Chapter Five, sustaining hope and providing the means to generate a positive identity as a mother.

When examining women's experiences of antenatal care earlier in this chapter and in Chapter Five, I highlighted the importance of the interpersonal dimensions of care, framing it within Mol's "logic of care" (2008). Many women built strong relationships with their HIV antenatal care team that were founded upon trust and imbued with affective qualities. This went a long way in fostering confidence in HIV clinical services as a whole, encouraging women to return for care, especially if they had been diagnosed during the current pregnancy and had limited experience of the hospital's HIV service. For many women, being transferred back into the general HIV clinic involved moving their care from the team involved in the antenatal clinic to a different set of healthcare professionals. The majority of women I interviewed had been diagnosed with HIV before their current pregnancy, and had attended the HIV clinic regularly prior to becoming pregnant. For these women, a return to the general HIV service was an opportunity to re-engage with staff who they had built long term relationships with, one woman describing it as "like going back home, kind of". Relationships with HIV specialist staff were characterised by care, with one woman telling me that her doctor was "doing her job with love". This was contrasted with staff in other disciplines who were felt not to be doing their job "from the heart" but "because they want to pay their bills and rent".

There were also practical ways in which women were encouraged to attend for follow-up after delivering their baby. For many, the arrival of a new baby heralded a period of upheaval especially if they were sole carers for their children. In the midst of caring for children, women were at risk of forgetting appointments and valued reminders. These prompts sometimes came from supportive partners, but often came from clinical staff, which made women feel valued and cared for. In one NHS clinic, this process had recently been formalised with the development of a new specialist nurse clinic designed specifically to engage women in care postnatally and to work with those who failed to return to elucidate barriers. In another clinic, women were provided with vouchers for formula feed and equipment by the general HIV clinic in the late stages of pregnancy and up to twelve months after delivery. Staff noted that the introduction of this scheme had allowed women to become familiar with the general HIV clinic during pregnancy, if they had not attended before, and incentivised them to return for follow-up. Assistance with access to benefits and emergency funding provided further incentives for women to come back, demonstrating (as in Chapter Five) that engagement in medical care is often dependent on attending to the broader context of patients' lives (Helman 1984, Mol 2008).

8.3.2 Staying away

But what of those of don't return for care after pregnancy? Healthcare professionals regularly identified postnatal attrition as a major problem in their clinics. The quantitative findings presented in this chapter challenge the common perception that women do not engage with HIV care after pregnancy. One explanation for the discrepancy between clinicians'' perceptions and the epidemiological data is that those working in healthcare are likely to preferentially recall cases where women have not returned. Although none of the women I interviewed postnatally had disengaged from HIV care, many had heard of others who had or had opinions on what may prevent women from returning. We have seen that a key determinant in a woman's willingness to continue to engage in care is her experience of care during pregnancy. When the relationship with healthcare professionals flounders, women's trust in the healthcare system flounders with it. The failures to maintain confidentiality, neglect of care and experiences of stigma and discrimination from healthcare professionals described in the preceding chapter, may instil fear in some women, discouraging them from returning for follow-up. As discussed earlier, HIV-related stigma often operates synergistically with other forms of exclusion such as racism, and gender and class inequalities. African women living with HIV may experience greater levels of stigma and discrimination in health settings, and thus have more grounds to fear returning for care.

Anxieties about stigma and discrimination were not just confined to the hospital setting. As explored in Chapter Five, HIV-related stigma is likely to vary between African communities, largely as a result of HIV prevalence, ART coverage and cultural factors such as the moralising influence of religion. Evidence from the literature (Genberg et al. 2009, Winskell et al. 2011) and my fieldwork (see Chapter Five) suggests that stigmatising attitudes towards HIV may be more prevalent in West African communities. Women from West Africa may therefore find disclosure of HIV status especially difficult. Regular attendance for HIV care during pregnancy is facilitated by the fact that this is a common feature of all pregnancies in the UK, allowing a woman to conceal her HIV status from those around her. Attendance for care after pregnancy has ended, however, may prompt questions from partners and family that women may find difficult to answer. This may be particularly difficult for women who have recently arrived in the UK or who have insecure immigration status, as they are often dependent on partners and family for financial support and their immigration papers as described in Chapter Five. Lack of financial independence and citizenship rights compel women to manage information about their HIV-positive identity, fearing that disclosure will threaten an already precarious existence. Facing the very real risk of abandonment and social ostracism, it is therefore unsurprising that some women may choose not to return to the HIV clinic when the stakes are so high. The problem is compounded by the fact that the HIV clinic may be identifiable as such. Some women made a clear distinction between HIV antenatal care and care after pregnancy. In two of the hospitals I worked with, HIV antenatal care was provided in the hospitals' general antenatal clinic. Women described their relief at being able to seek care in an environment that did not mark them out as HIV-positive, affording them privacy they may not experience in the general HIV clinic:

In the antenatal clinic there were many of us. No one knew why you were there. Here [the HIV clinic] people see you. There's even a lady who works here who I know from college. It was more private with my [specialist midwife].

(Patience)

Attending for follow-up at a clinic that is known to look after HIV-positive patients, may therefore compromise a woman's ability to pass as HIV-negative and risks inadvertent disclosure and its attendant sequelae. Of note, HIV exceptionalism was also felt by members of staff who spoke of its "separateness…its exclusivity…its secretiveness". One HIV physician commented on the location of the HIV clinic "on the back of the hospital", perhaps symbolic of HIV medicine's marginalisation as a discipline within the hospital. This same physician enjoyed working in her HIV antenatal clinic as geographically she was situated within the hospital's main building and worked with members of the hospital's wider team. If HIV clinicians find normalcy in working within the antenatal clinic, is it perhaps unsurprising that their patients share the same feelings. The arrival of their baby heralded a time of great personal joy for women, especially as it allowed them to continue on a culturally defined life trajectory. This excitement may result in HIV receding from women's lives, in some cases manifesting in denial of their HIV status. The return to routine HIV care after pregnancy, often in a dedicated unit, may therefore function as a jarring and painful reminder of women's HIV status at a precisely a point in their lives where they have achieved a degree of normalcy through motherhood.

In Chapter Five, I explored the resilience women living with HIV demonstrate during pregnancy in terms of accessing care and taking ART. Postnatally, some women may find themselves less motivated to attend for care for themselves, safe in the knowledge that they have secured an HIV-negative baby. At this point, a woman's own HIV disease may become relegated in the hierarchy of needs (Maslow 1943), submerged by the exigencies of day-to-day life as a migrant woman in London. This may be especially the case for women who do not require ART for their own health after pregnancy. Some women described not returning for follow-up after previous pregnancies as their ART had been stopped[281]. They had felt that HIV care was intrinsically tied to the provision of ART and that stopping treatment was an indication that they were well and no longer required regular check-ups. The link between ART and engagement in care is supported by data presented earlier (tables 8.2 - 8.4), revealing that women with higher CD4 counts at the end of pregnancy, who may have been advised to discontinue ART, were less likely to return for follow-up[282].

We have seen that African women, especially those who had recently arrived in the UK and who were also likely to have insecure immigration status, were at greater risk of not returning for HIV follow-up after pregnancy. For many women interviewed, this was due to structural constraints. Women who were in the asylum process and were waiting for a decision on their application faced the threat of being dispersed to other parts of the country. As discussed earlier, continuity is an important factor in retaining women in care. Having forged strong relationships with staff at their clinic, the thought of building trust in another centre was a source of great anxiety, with some women stating that they would be reluctant to attend a new service. Those who existed outside the asylum system, either because they had entered the country illegally or had had their application for leave to remain rejected, had no entitlement to free HIV care following the delivery of their child[283]. Yet again, the structural violence described in Chapter

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[281] Short term ART is used during pregnancy in women whose CD4 counts do not meet the threshold for continuing treatment.

[282] The association between *not* being on ART and loss to follow-up has previously been reported in the overall HIV-positive population in the UK (Rice et al. 2011).

[283] At the time of my fieldwork free HIV treatment was denied to undocumented migrants, some refused asylum seekers, those on visitor visas and visa overstayers. The amendment to the Health and Social

Five, in the form of legal frameworks that legitimise unequal access to HIV care, comes to be embodied by HIV-positive migrant women. Throughout my fieldwork and clinical practice I encountered high levels of destitution among women who had migrated to the UK, and this was most acute in those who did not have leave to remain. Poverty, especially in the context of new motherhood where precious resources are directed to providing for children, is an important barrier to accessing healthcare when faced with, at the very least, finding money to pay for transport costs, and at the very worst exorbitant bills for medical care.

8.4 Conclusions

In this chapter I have used data from the NSHPC and my ethnographic fieldwork to explore African women's engagement with HIV services *after* pregnancy. In contrast to the widespread clinical perception that women are lost to follow-up postnatally, nearly 90% of women returned for HIV care after pregnancy, many motivated by the desire to secure a future for themselves and their family through maintaining good health. Of the small proportion of women who did not return for HIV care, African women, especially those from Southern and Western African and those who arrived in the UK after conception, were at the greatest risk of being lost to follow-up. Poor experiences of healthcare and the fear of being seen to attend a service known to provide care for those living with HIV may be important barriers as is the discontinuation of ART after pregnancy. Structural constraints also play a central role whether it be the corrosive effects of poverty that relegate healthcare to the bottom of women's hierarchy of needs or the structural violence of laws that denied access to ART to those without citizenship rights. Again, the dual forces of stigma and structural violence act to constrain some African HIV-positive women's access to healthcare and shape their experiences, placing their long term health and that of their babies' at risk.

Key points

- Nearly 90% of HIV-positive women returned for follow-up in the year after pregnancy, mainly motivated by the desire to maintain their health and the good relationships they had fostered with their HIV antenatal teams.

- Of the small proportion (12.5%) who did not return for HIV care, African

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Care bill which removed charges for HIV treatment to all overseas visitors came into force in October 2012 after my fieldwork had ended and therefore had no impact on my participants at the time of interview.

women, especially those from Southern and Western African and those who had arrived in the UK after conception, were at the greatest risk of being lost to follow-up.

- Barriers to longer-term engagement in HIV care after pregnancy may include poor experiences of healthcare, fear of disclosure of HIV status and structural factors, especially the lack of provision of free HIV care to overseas visitors up until October 2012.

9

Infant feeding among African women living with HIV in the UK

Summary

Current guidance in the UK advises HIV-positive women to avoid breastfeeding their children in order to minimise the risk of vertical transmission. Although studies examining infant feeding decision-making among women living with HIV have been conducted in resource-poor settings, very little is known about how it affects women in countries such as the UK. In this qualitative chapter I draw upon data from interviews with African women living with HIV and professionals involved in their care to explore decision-making about infant feeding in the context of HIV. Embedding my analysis within a theoretical framework of the social construction of risk, I explore the structural and cultural context of decision-making about infant feeding. I then discuss the impact of *not* breastfeeding on women, particularly focusing upon repercussions within the social domain and conclude by tracing emerging resistance in women to guidelines on infant feeding in the UK.

9.1 Introduction

Previous chapters of this thesis have explored how decisions about ART, access to health services and wider notions about health and illness among African women living with HIV in the UK are embedded within a complex sociocultural matrix. In these chapters, stigma, structural violence, faith and their location within transnational African communities emerge as important factors in shaping HIV-positive women's experiences of pregnancy and their engagement with care. Breastfeeding is an important route of vertical transmission of HIV, with the risk estimated to be between 14 to 29% (Dunn et al. 1992), contributing to between one third and a half of all new HIV infections in children globally each year (World Health Organisation et al. 2007). In this chapter I wish to build upon my analytic engagement with social factors by focusing on a different aspect of pregnancy and motherhood – infant feeding decision-making.

The risk of vertical transmission postnatally varies depending on feeding patterns. For reasons that are not fully understood, mixed feeding (which is feeding an infant breast milk *and* either non-human milk, other liquids or solids) (World Health Organisation 2001a), carries a greater risk of HIV transmission than exclusive breastfeeding, defined as no other food or drink including water apart from breast milk (Coutsoudis et al. 2001). Exclusive formula feeding eliminates the risk of postnatal vertical transmission through feeding; however it requires access to affordable formula-feed, clean water and sterile equipment. In resource-poor settings exclusive formula feeding presents significant operational challenges and has been shown to result in increased infant mortality secondary to diarrhoeal illness and malnutrition, when compared with exclusive breastfeeding (Iliff et al. 2005, Coovadia et al. 2007). Current WHO guidelines on infant feeding and HIV (World Health Organisation 2001b) therefore advise that formula feeding be recommended to HIV-positive mothers if it is acceptable, feasible, affordable, sustainable and safe[284]. In many resource-poor settings, these criteria are not met and women living with HIV are advised to exclusively breastfeed their infants for six months. The use of maternal HAART has been shown to reduce the risk of vertical transmission through breastfeeding to between 0 and 5% (Kilewo et al. 2009, Peltier et al. 2009, Homsy et al. 2010, Shapiro et al. 2010, The Kesho Bora Study Group 2011, Jamieson et al. 2012) and is recommended by the WHO for women who breastfeed in the context of HIV (World Health Organisation 2009b).

In resource-rich settings such as the UK, widespread access to clean water and availability of formula-feed means that the risk of vertical transmission of HIV outweighs that of other infant morbidity such as malnutrition and diarrhoeal illness. Since 2001, UK guidelines have recommended exclusive formula feeding and the avoidance of breastfeeding for all women diagnosed with HIV (Lyall et al. 2001, Hawkins et al. 2005, BHIVA/CHIVA Guidelines Writing Group 2010, Taylor et al. 2012). Although current UK guidelines recognise that the risk of vertical transmission through breastfeeding is reduced through the use of maternal HAART, concerns remain about the small residual risk of transmission and the lack of data on long-term effects in infants of exposure to ART through breast milk. Where a mother has an undetectable viral load on ART and chooses to breastfeed, UK guidance advises careful monitoring of both mother and child and cessation of breastfeeding by six months (Taylor et al. 2012: 131). This is the only situation currently in which breastfeeding in the context of

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[284] This set of criteria is widely known by the acronym AFASS.

HIV is not viewed as grounds for automatic referral to child protection services (Ibid., 131).

Data I have extracted from the NSHPC dataset reveals very low rates of documented breastfeeding between 2000 and 2010 among women living with HIV in the UK (210/6608, 2.0%). These data may be unreliable as breastfeeding history was not documented in over a third of infants and small numbers preclude further meaningful statistical analysis. Furthermore, given the clear medical recommendation to exclusively formula-feed, women may not feel able to disclose that they have breastfed their infants. However, the fact that seroconversion to HIV is extremely rare in infants who have had a negative test at birth (a marker of postnatal transmission) (Janet Masters, UCL Institute of Child Health, personal communication, 13 December 2011), coupled with the consistently low rate of vertical transmission in the UK (Townsend et al. 2013), suggest that the overwhelming majority of mothers in the UK who are diagnosed with HIV avoid breastfeeding.

Although there is evidence that the majority of HIV-positive women in the UK adhere to UK guidelines, the avoidance of breastfeeding brings with it a host of other consequences. During my fieldwork, women often raised the subject of infant feeding unprompted. These sections of my interviews were often the most emotive, encompassing marked feelings of guilt, fear and despair. Numerous studies conducted within resource-poor settings have highlighted the structural and sociocultural constraints experienced by HIV-positive women when making decisions about how to feed their babies (Moland 2004, Doherty et al. 2006, Blystad et al. 2009, Desclaux et al. 2009, Koricho et al. 2010, Van Hollen 2011). It is widely acknowledged that in many of these settings infant feeding decisions are highly conflicted (Hausman 2011: 2), whereas there is often an assumption that formula feeding is more acceptable and feasible in resource-rich settings[285]. This assumption is reflected by the absence of literature emerging from resource-rich settings that engage with the realities of infant feeding decisions and HIV, with the notable exception of a recent but unpublished study conducted among HIV-positive mothers in Canada[286]. To date, no work in the UK has explored the issue of infant feeding in the context of HIV systematically.

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[285] For example Hausman's assertion that formula feeding is "an accepted and ordinary practice in the United States and other industrialised countries [and that] women are not ostracized (or stigmatized as HIV-positive) as a result of feeding their babies with bottles" (2011: 191).

[286] In this study of twenty-seven women in Ontario, Canada, the authors highlight how decisions about infant feeding by HIV-positive women are culturally, socially and politically contingent, and the difficulties encountered in avoiding breastfeeding (Greene, et al. 2012).

In this chapter I present the first ethnographic study in the UK to explore infant feeding decisions among HIV-positive mothers, with specific reference to African migrant women, drawing primarily upon interviews with African women living with HIV and professionals involved in their care. Grounding my analysis in feminist writing on infant feeding and anthropological work on the social construction of risk, I aim to demonstrate how infant feeding decisions by HIV-positive women are generated within a social domain, and how the profoundly relational nature of this decision-making impacts on women socially in terms of stigma, social isolation and loss of social status.

9.2 Theoretical frames

Infant feeding (regardless of HIV) has become primarily a public health concern, reflecting the medicalisation of human life that is the hallmark of Foucauldian biopolitics (Foucault [2003] 1963). Of course infant feeding, whether it be breastfeeding, formula feeding or feeding with other types of food, has important health and nutritional consequences. However, this medicalisation has resulted in the biomedical aspects of feeding being privileged in contemporary discussions of infant feeding. Furthermore, the portrayal of infant feeding as a health-related intervention invites it to be viewed as "value-neutral" (Hausman 2011: 37)[287]. Yet, as highlighted by Linda Blum (1999) in her sociological analysis of the "ideologies of breastfeeding and motherhood" in the United States, the decision about how to feed your baby is rarely "value-neutral". Blum describes how dominant ideas on infant feeding are inextricably linked to the economic and political aims of the nation-state and the need to have productive mothers in the workforce and secure healthy future citizens[288]:

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[287] In her analysis of the discursive construction of mothers living with HIV with particular reference to infant feeding, Hausman specifically places infant feeding in the context of Foucauldian biopower, describing the medicalisation of breastfeeding both in the United States (in the form of the 2004 U.S National Breastfeed Campaign) and the public-health response to the risk of vertical transmission through breastfeeding (2011). Blum's work on the sociohistorical construction of infant feeding in the United States as a legitimate state and public health concern in the early twentieth century is also relevant here (1999).

[288] In this work, Blum also describes how the popularity of formula feeding in the US in the mid-twentieth century coincided with increasing medical advances and interest in the scientific properties of milk, the rise of technological advances as emblematic of modernity and the growing role of women in the workplace. In contradistinction, the resurgent popularity of breastfeeding in the US in the late twentieth century was underpinned by a broader feminist movement against the medicalisation of female bodies and the 'back to nature' messages of counterculture, as well as increasing medical evidence of the medical benefits of breast milk.

"Breastfeeding does not have inherent truth, but meanings determined out of power relations, various disciplining practices, and conflicting needs and interests, which are inherently political."

(Blum 1999: 200)

This is echoed by work from South Africa revealing how breastfeeding is absorbed into ideologies of nation-state in KwaZulu-Natal, where women are exhorted to "breastfeed for a healthy nation" (Seidel 2000)[289]. Furthermore breastfeeding, and by implication its counterpart formula feeding, are inherently social and invested with symbolic power as a "biosocial practice linked to other aspects of material life and their meanings [with] an important role in local cultural meaning systems" (Hausman 2011: 142). As Donna Haraway so eloquently states, "breast milk is not the nature to the culture of Nestlé's formula" (Haraway 1988: 209). My aim in this chapter is to explore the meanings of breastfeeding and formula feeding among African women living with HIV in the UK, taking my starting point as both being "natural-technical objects, embedded in matrices of practical culture and cultural practice" (Haraway 1988: 209); biological substances imbued with signifying power in which "mind, body, and tool are on very intimate terms (Haraway 1991: 165).

A second important theoretical frame for this chapter is the social construction of risk. Decisions about infant feeding in the context of HIV predominantly encompass questions about risk. The risk of a child becoming infected with HIV, of a child not receiving adequate nutrition, of reduced bonding between mother and child, and a host of other social risks that will be explored in detail later in this chapter. A dominant paradigm in the conceptualisation of risk within the public health arena is the *technical approach* to risk (Rhodes 1997, Tansey et al. 1999) which pertains to the calculation of risk in an effort to ensure safety (Rhodes 1997: 72). The assumption underlying this approach is that decisions about risk are made by an individual, that these are rational choices underpinned by the utility principle[290] (a cost versus benefit analysis), and that individuals are free to make these choices. Those who do not subscribe to the consensus about dangers are thought to be irrational or poorly informed, requiring

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[289] Seidel sees the global anti-formula milk action in the 1970s that was concentrated in many parts of Sub-Saharan Africa as an important influence in continuing emphasis on the importance of breastfeeding in this context (2000).

[290] The utility principle is central to economic rationalism, which dominates twenty-first century global politics and asserts that individuals balance cost against benefits in order to maximise their personal advantage (Tansey et al. 1999).

education to redress these perceived poor choices (Douglas et al. 1983, Douglas et al. 1990). However, the technical approach has important limitations in that it fails to take into account the following: that humans are predominantly social beings and that decisions about risk are relational; that risk is socially constructed; and that issues of power may act to constrain people's capacity to make choices. The cultural theory of risk provides a more useful analytic entry point into thinking through decision-making about infant feeding in the context of HIV. A key reference here is Douglas and Wildavsky's "Risk and Culture" (1983) on the social construction of risk. With specific reference to the predominance of concerns regarding environmental dangers in the contemporary United States, Douglas and Wildavsky do not ignore risk as fact but ask us to consider "on what basis are certain dangers guarded against and others relegated to secondary status" (Ibid.: 1)[291]. How and why we come to see things as risky is not a value-neutral judgment centred upon costs and benefits, but instead is deeply socially embedded[292]. Given the social construction of risk it therefore follows that decisions about what is risky and how to address this are predominantly social processes. This is particularly important when considering decision making about health-related risks as "the credibility of health-related messages will (all) be influenced by the interactional context in which judgements are made" (Tansey et al. 1999: 72)[293]. Douglas and Wildavsky highlight the importance of social context in addressing questions about risk:

> ""The perception of risk is a social process. All society depends on combinations of confidence and fear. Learning about fear ought to afford a backdoor route for understanding confidence. […] In addressing questions of acceptable risk without considering their social aspects, we could be speaking to the wrong problem."
>
> (Douglas et al. 1990: 6)

The social organisation of risk has been explored before within HIV, generating important insights into "high risk" behaviours. Work addressing risk-taking behaviour

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[291] Douglas and Wildavsky's analysis of the social construction of risk builds upon Douglas' previous work on pollution and taboo, which I drew upon in Chapter Seven when writing about stigma and discrimination experienced by women in maternity services. In "Purity and Danger" ([2002] 1966) Douglas describes how the creation of the domain of the polluted is an inherently symbolic process with rules governing what constitutes bodily pollution and danger likely to symbolising deeper preoccupations with social structures.

[292] For instance, Douglas and Wildavsky describe how preoccupations with environmental risks were borne of a particular time in history characterised by rapid technological innovation, changes in social structures, and growing suspicion of central institutions.

[293] Tansey and O'Riordan's 1999 review is a useful summary of the theoretical roots of cultural theory and risk and is application to health-risk management (1999).

among men who have sex with men, specifically barebacking[294], has revealed that decisions to have sex without a condom are less about lack of awareness of health-risks and more bound up with concepts of masculinity, erotic fantasies, issues of power and emotional factors such as the building of trust and intimacy with sexual partners (Ridge 1996, Ridge 2004). Similarly, when looking at sexual and injecting risk-taking among people who use drugs in London, Rhodes found that risk-taking was again not borne out of poor knowledge but instead was shaped by the exigencies of illicit drug use, gender based violence, behavioural norms and the desire to forge intimate bonds (Rhodes et al. 2005).

Throughout this chapter I will be drawing upon these theoretical frames to explore the social meanings of both breastfeeding and formula feeding and how decisions that my participants made about feeding their babies were located within a social domain, rather than being based purely on a value-neutral rational assessment of risk versus benefits. My intention is that the understanding of the social dimensions of infant feeding decisions in the context of HIV will inform the development of support for women when making these difficult decisions.

9.3 Breastfeeding as risk

Current UK guidelines advise the complete avoidance of breastfeeding in women living with HIV (Taylor et al. 2012) in order to eliminate the risk of postnatal transmission of HIV and to avoid the unknown long term risk to infants of exposure to ART in breast milk. Of the fifteen women I interviewed postnatally, only one described breastfeeding her infant[295]. Of the remaining nine women who were not interviewed postnatally, all stated an intention to avoid breastfeeding completely. My participants were knowledgeable about the risks of breastfeeding and emphasised the paramount importance of minimising the risk of HIV transmission to their child[296]. Whilst not denying the reality of this risk, it is important to explore how the risk of breastfeeding in the context of HIV is socially organised. For instance, why is breastfeeding prioritised as an important risk to the health of a child over other factors such as late antenatal booking[297], which passes with virtually no comment?

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[294] Anal intercourse without a condom.

[295] This case will be discussed in detail later in the chapter.

[296] This is echoed by work presented in Chapter Five on the importance of securing an HIV-negative child as a prime motivation to take ART during pregnancy.

[297] In my overview of literature (Chapter Two) I described how late antenatal booking in the general obstetric population is associated with poorer maternal and infant outcomes. I also presented data in

In Chapters Five and Seven I highlighted how the HIV-positive pregnant female body may come to be viewed by professionals and mothers as unreliable, posing a threat to the safety of the foetus and requiring surveillance with procedures such as blood tests and foetal ultrasound imaging. This manifestation of biopolitics extends into the construction of the postnatal HIV-positive body as potentially threatening, requiring regulation in terms of guidance to avoid breastfeeding, despite the risk of transmission for a woman stable on ART estimated to be low at between 0 and 5%. This notion of the HIV-positive maternal body as a source of danger becomes embodied by women and is a source of distress:

Because I was told that if you breastfeed [you can transmit HIV to the baby] I just felt like if I did anything with the baby maybe the baby will be in harm's way. I was just scared of everything else so it caused quite a lot of stress for me. I think that's how I actually managed to start having depression.

(Charity)

Women’s concerns about the risk they pose to their children echo the primacy of the foetus and child in biomedical discourse on reproduction[298] and societal anxieties about the dangers mothers pose to their children. The notion of breast milk as risky is not only biological fact but a social phenomenon constructed through interaction with professional institutions. As Douglas and Wildavsky write:

“In risk perception, humans act less as individuals and more as social beings, who have internalised social pressures and delegated their decision-making processes to institutions. They manage as well as they do, without knowing the risks they face, by following social rules on what to ignore: institutions are their problem solving devices.”

(Douglas et al. 1990: 80)

In the Chapter Seven I explored the symbolic basis of stigma and discrimination towards HIV-positive women within maternity services. Using the work of Mary Douglas and Julia Kristeva, I argued that the pregnant HIV-positive woman occupies a

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Chapter Seven demonstrating that nearly one in two HIV positive women in the UK presented late to antenatal care between 2008 and 2010.

[298] Hausman draws a parallel between public health concerns in the US surrounding the transmission of West Nile Virus and the increasing medicalisation of the female reproductive body. In this discourse, the technical approach to risk leads to an emphasis on risks of harm to the child, impelling women to subscribe to medical guidance and intervention in order to safeguard their children’s health despite little evidence that this posed a great risk (2011:70).

symbolically anomalous place challenging the simple binary oppositions of illness and health; death and life; joy and sorrow; responsibility and recklessness. Furthermore the physical facts of pregnancy and lactation make the maternal body physically and symbolically permeable, collapsing the rigid boundaries of the human body and exacerbating fears about pollution. Indeed the ambiguous nature of an HIV-positive mother's breast milk renders it a *pharmakon* (Hausman 2011: 29), at once both nourishment and danger. I suggest that the biomedical emphasis on an HIV mother's breast milk as a dangerous substance, whilst rooted in biological fact, is informed by these symbolic meanings.

The preoccupation with the maternal body as a site of potential danger is also reflected in wider concerns about the risks that woman may pose to their babies during pregnancy and motherhood, exemplified by recent medical guidance that women minimise risk through the avoidance of exposure to a host of everyday chemicals[299]. This concern with environmental danger is in itself informed by the construction of environmental pollution as an important risk in contemporary society as described by Douglas and Wildavsky (1983). In this discourse, a woman's body ceases to exist in its own right and becomes uncoupled from other aspects of her life. Her primary responsibility is to ensure the safety of her child by regulating and policing her own body, avoiding toxins and withholding her body from her child if that is not possible. It is therefore unsurprising my participants presented the decision to avoid breastfeeding as a duty rather than choice, feeling that they would be ultimately responsible if their child became infected with HIV:

I'm always thinking about it [breastfeeding]. I'm thinking [...] like maybe I will just try [...] but then I always have it in my head, 'So what if something happens to the baby?' Then it's going to be something that I will never forgive myself for.'

(Matilda)

9.4 Situating feeding decisions

If decisions about infant feeding were wholly centred upon the avoidance of risk of

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[299] A recently published scientific impact paper by the Royal College of Obstetrics and Gynaecology seeks to raise awareness of issues surrounding exposure to common chemicals (such as household cleaning products, herbal remedies, pesticides and personal care products) in pregnancy. This paper concludes that in the absence of data about the risks that these chemicals pose that women should employ "a safety first approach, which is to assume there is risk present even when it may be minimal or eventually unfounded" (Royal College of Obstetricians and Gynaecologists 2013).

vertical transmission, we might expect decisions to be straightforward. However, although almost all the women in this ethnography avoided breastfeeding their babies, the decision was often fraught and characterised by feelings of guilt, sorrow and fear.

Breastfeeding can be an intensely enjoyable experience for women (Leff et al. 1994, Schmied et al. 1999) yet this pleasurable aspect of feeding is often overlooked. Some participants mourned the loss of the physicality of breastfeeding:

I didn't like looking at women breastfeeding and sometimes I used to just put him [her son] on my breast even though there was nothing [no milk] there just to see how it would have felt.

(Faith)

The majority of work on breastfeeding comes from a biomedical and public health paradigm. Studies that engage with women's embodied experiences of breastfeeding remain rare. Dominant notions of the asexual nurturing maternal body result in the muting of discussions of breastfeeding as a sensual and potentially erotic experience involving "intense physical exchanges: skin touching, hands stroking, holding and playing, bodies sharing, hormones pulsing, as well as an emotional relation of intimacy, care and often passionate engagement" (Bartlett 2005: 68)[300]. On a broader level, this reflects a tendency to neglect pleasure in sexual and reproductive health research, especially among women (Hirsch 2007).

In abstaining from breastfeeding my participants felt an acute sense of personal loss, often crying when discussing their decision to formula-feed and describing themselves as "sad", "unhappy" and "devastated". It was clear that avoiding breastfeeding came at significant emotional cost:

The big issue when I was diagnosed was thinking about not being able to breastfeed. I mean it kind of disturbed me a lot [...] With the first child it kind of hit me big time. I used to cry about that; I used to cry about that you know.

(Esther)

Furthermore, the decision to abstain from breastfeeding was not an isolated event; rather it was a process that continued throughout infancy. Women often found themselves

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[300] Bartlett also outlines the sociohistorical factors that have led to the subjugation of maternal sexuality.

revisiting their decision either on feeding their baby or when questioned by others as to why there were not breastfeeding. This served as a painful and tangible reminder of their HIV-positive status:

At times you want to forget this thing HIV. If you keep explaining you have to tell lies […] within yourself. It's a kind of emotional trauma.

(Bolade)

The structural marginalisation of some of my participants further contributed to the difficulties encountered in adhering to medical advice to avoid breastfeeding. Women highlighted the work involved in formula feeding in terms of preparing equipment and feeds. For those who were sole carers, often with other small children to look after, the demands of formula feeding without the support of a partner were especially great. Furthermore on migrating to the UK, many had left behind kinship networks at home that they could ordinarily draw support from. The reality was that formula feeding their newborn baby was a solitary and laborious endeavour.

An even greater challenge to the avoidance of breastfeeding was the significant cost of formula-feed and feeding equipment[301]. As discussed in Chapter Five, destitution and food insecurity was common among my participants. Those on low-incomes with secure immigration status qualified for state-funded financial assistance, which provides vouchers for the purchase of formula. For those whose income level was not at the threshold of state-assistance, buying formula often put a strain on already stretched household finances:

The formula is very expensive and you're thinking, 'Oh my God, if I was breastfeeding I wouldn't be spending so much money on just buying milk all the time.' At some point we [her and her partner] could not afford it [...] it was so expensive.

(Faith)

Women with insecure immigration status and no recourse to public funds found

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[301] Many studies from resource-poor settings illustrate how poverty renders the purchase of formula-feed impossible (Chivonivoni, et al. 2008, Thairu, et al. 2005, Hofmann, et al. 2009, Doherty, et al. 2006). This is especially the case for women who lack financial support from partners or families (Chisenga, et al. 2011, Seidel 2004). Indeed, the corrosive effects of poverty extend beyond the family unit as women may find that clinic stocks of formula routinely run out (Doherty, et al. 2006). The structural constraints to formula feeding in resource-rich settings have up until now been overlooked.

themselves in an even more precarious situation. At the time of my fieldwork, the British HIV Association had released a position statement on infant feeding in the context of HIV in which they advised the provision of free formula to women without recourse to public funds through locally negotiated schemes (BHIVA/CHIVA Guidelines Writing Group 2010). In reality the availability of such schemes was patchy, with one of my NHS fieldwork sites having no system in place to provide free formula and equipment to women who were unable to afford it[302]. Women without secure immigration status were often forced into financial dependency on friends, family and partners, who were sometimes unaware of their HIV status, and were unwilling to provide financial assistance:

I've had another woman who was living with a sort of relative who kept on at her for months. She had no money, no resources. She was an overstayer[303] and she kind of had to stay there and put up with it but she [the relative] was always telling her that she was a bad mother and asking 'why are you spending money on milk?' when she hasn't got any money.

(Carol, HIV specialist midwife)

Yet again, as seen in previous chapters, the structurally violent forces of poverty and immigration law combine to constrain the ability of women without secure immigration status to engage with important HIV-related health interventions, rendering their lives and those of their babies "bare" (Agamben 1998).

In addition to the personal attachment to breastfeeding and the structural constraints outlined above, many participants expressed a strong belief in the superiority of breast milk over formula describing it as "important", "the best", "natural" and "good". Breastfeeding was strongly identified with "African" culture by women:

Sometimes I feel it's so hard…that's what really makes me feel sad when I look at my baby, as a black woman, because in our culture in Africa you're supposed to breastfeed for two years.

(Mariama)

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[302] It will be interesting to see whether the recent publication of the British HIV Associations standards of care for people living with HIV, which explicitly states that free infant formula be provided to all women who cannot afford it, results in a more consistent provision of support to mother living with HIV (British HIV Association 2012).

[303] Someone who has remained in the UK beyond the expiry date of their visa.

In many regions of Sub-Saharan Africa breast milk is seen as superior to all other sources of infant nutrition (Moland 2004, Thairu et al. 2005, Chivonivoni et al. 2008, Moses et al. 2009). Earlier in this chapter I drew upon work on infant feeding to highlight the fact that breast milk is not only a biological substance but also a symbolic object invested with social meaning (Haraway 1997, Blum 1999, Hausman 2011). For example, among the Chagga in Northern Tanzania, breast milk is embedded within an elaborate symbolic network of bodily fluids and is seen as a powerful, "life-giving force", the feminine counterpart to semen (Moland 2004). Work conducted in Tanzania with Gogo women (Mabilia 2005) and with HIV-positive mothers in Malawi (Levy et al. 2010) illustrate how breastfeeding is often articulated in terms of its 'naturalness' and is understood to have unique nutritional qualities[304]. This is highlighted in Hofmann's ethnography of breastfeeding in rural Burkina Faso in which she draws our attention to the translation of *siindji* (the Djoula term for breast milk) as "the water that supports and preserves life" (2009). An important contributing factor to the perception of breast milk as superior to infant formula throughout Sub-Saharan Africa is the highly contested issue of formula feeding throughout the continent in latter half of the twentieth century[305]. Many of the women I interviewed grew up in African countries during the 1970s and 1980s, an era characterised by widespread efforts by activists, public health professionals and NGOs to educate communities about the benefits of breast milk and the dangers of formula.

However to cast the cultural construction of breast milk as superior to formula as a purely African phenomenon is erroneous. The pro-breastfeeding movement is both successful and international as exemplified by organisations such as the World Breastfeeding Alliance and La Leche League[306]. In resource-rich settings breast milk is idealised, cast in biomedical terms as optimal in terms of its immunological and nutritional qualities[307]. In the UK it is the norm for most women to attempt to

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[304] Also see Moland 2004, Buskens, et al. 2007, Pool, et al. 2001.

[305] Throughout the mid-twentieth century, multinational companies targeted resource-poor countries with aggressive marketing for infant formula. However uptake of formula feeding was associated with increasing numbers of infant deaths secondary to diarrhoeal disease, malnutrition and dehydration as a result of lack of clean water. This led to the Nestlé Boycott from the 1970s onwards coupled with widespread education about the benefits of breast milk and the dangers of formula-feed, underpinned by a suspicion that Western institutions endorsing infant formula formed part of a grand narrative of post-colonial exploitation (Baumslag, et al. 1995).

[306] Both these international organisations seek to support and promote breastfeeding through both policy, and more locally through education and peer support programmes. For further information see their websites at http://www.waba.org.my/ and http://www.llli.org/.

[307] See Blum (1999) for a detailed description of the social organisation of breastfeeding in the United States and women's experience of their bodies as "failing" if they are unable to meet this ideal.

breastfeed with rates of initial breastfeeding[308] of 81% (The NHS Information Centre et al. 2011). We therefore live in an era of globalised "ideologies of breastfeeding" (Blum 1999) with women in diaspora being exposed to specific local articulations of this ideology in both their home countries and the UK.

Women are also active agents in seeking information about infant feeding, drawing upon a host of sources including print media and the internet[309]. Many of my participants had consulted books and the internet and had concluded that breastfeeding was superior to infant formula in terms of infant nutrition and long-term development. They were further exposed to pro-breastfeeding messages when attending for antenatal care. Although my participants were seen by an HIV specialist antenatal team, geographically their clinics were located within the general hospital antenatal service. The high visibility of pro-breastfeeding posters and literature in general antenatal services, whilst understandable from a general public-health perspective, meant that HIV-positive women are often exposed to messages that were not tailored to their circumstances as HIV-positive expectant mothers. The benefits of breast milk were reinforced within the antenatal classes that some of participants attended, which again were aimed at a predominantly HIV-negative group of women.

African women living with HIV are therefore subjected to a variety of discourses that valorise breastfeeding. For many, breastfeeding was intrinsically tied to a positive identity as both a mother and as a woman:

> *I feel unhappy [about not breastfeeding]. But if I do not breastfeed, my baby might be okay. So I just accept it but in my heart it pains me because as a woman you have to breastfeed your baby.*
>
> (Hope)

Women described feelings of guilt and selfishness despite the fact that they were avoiding breastfeeding at great personal cost in order to safeguard the health of their baby. Not only were their internal expectations of motherhood disrupted by avoiding breastfeeding, but they also had to contend with the expectations of those around them

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[308] This definition includes all babies who were put to the breast at all, even if it was only once.

[309] A recent study from Leeds has revealed that "HIV breastfeeding" is entered as a Google search term approximately 2900 times a month with 320 of the searches originating in the UK. The authors found that of the nineteen web pages, four were "pro-breastfeeding:" and did not make a clear distinction between resource-rich and resource poor settings. Of more concern was the finding that three sites contained grossly misleading information about the ability of breast milk to destroy HIV (Durba, et al. 2013).

either in the UK or on visits back home to Africa. Some described how their decision to formula-feed had led them to be viewed by others as "selfish" or "bad" mothers. Health professionals were acutely aware of the challenges their advice to avoid breastfeeding presented to the construction of a positive maternal identity:

What does motherhood look like when it's done well in the communities that have high rates of HIV? It's very hard to identify as a good mother if you follow the medical advice that I give out in many cases.

(Helen, HIV antenatal specialist doctor)

My participants subscribed to a global hegemonic notion of a good mother as a nurturing, selfless, *breastfeeding* mother. In Goffman's[310] ([1990] 1963) terms, abstaining from breastfeeding "spoils" a woman's identity as a good mother, both internally and externally, and places her in the realm of uncaring, selfish bad mothers, set apart from those who successfully adhere to the dominant cultural script:

I think that maybe I am not a part of these people, I feel so bad when I see them [women who breastfeed].

(Grace)

Breastfeeding was as a core component of motherhood that women had expected (and were expected) to perform, and had looked forward to. Bury (1982) has described the "biographical disruption" that people with chronic illness encounter. The long-term, or permanent, nature of chronic illness not only impacts upon a person's physical self, but also presents a challenge to their sense of identity. The onset of chronic illness brings with it a new world of symptoms, regimes, roles and meaning for an individual[311]. Pregnant women and mothers with living with HIV encounter a particular type of biographical disruption when confronted with infant feeding decisions. When HIV interacts with pregnancy it disrupts their expected trajectory through motherhood meaning that the relationship between expectations of motherhood and motherhood as it is enacted in the context of HIV are no longer congruent.

As touched upon earlier in this chapter, decisions about what is risky and how to

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[310] See Chapter One (36-37) for a more detailed description of Goffman's concept of spoiled identity.

[311] Green and Sobo (2000) have elaborated upon this to describe the biographical disruption that results from HIV in terms of both physical symptoms in a pre-HAART era and the highly stigmatising nature of the disease.

address this are predominantly social processes. For many of my participants, decisions about feeding their infants were socially embedded within their local social networks[312]. They described how it was the norm for families and members of their wider community to scrutinise and comment on mothers' feeding decisions. It was not uncommon for women's decision to formula-feed to be greeted with suspicion, demands for justification and even physical encouragement to breastfeed:

I am sure there are some who will breastfeed just to keep the family quiet because you would say to your mum, 'Oh the baby doesn't take to the breast very well' and then they [mum] will probably show you how to do it wouldn't they? So what do you do?

(Cynthia, HIV peer-support professional)

A central obstacle that women face when avoiding breastfeeding is that of disclosure of their HIV status. Avoidance of breastfeeding not only marked women as "selfish" mothers but also functioned as a marker of HIV-positive status[313], especially when coupled with other potential indicators:

You always have to explain [...] that this baby is taking medication and then that you're not breastfeeding. So everything adds up and even if people don't make comments you know it's [suspicions about HIV-status] just going to be out there.

(Faith)

Although most women I interviewed had disclosed to their partner, it was rare that they had informed other members of their family of their HIV status, let alone anyone else. The deep-seated stigma within many African communities[314] surrounding HIV led to the majority of women fearing the consequence of inadvertent disclosure of their status[315].

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[312] Studies from other settings (predominantly Sub-Saharan Africa) reveal how decisions about infant feeding extend beyond the mother-child dyad. Although spouses play a large part in decision-making (Moses, et al. 2009, Kasinga, et al. 2008, Buskens, et al. 2007), it is important to recognise that extended family and other members of the community, especially elders and grandmothers, may contribute to feeding decisions (Pool, et al 2001, Buskens, et al 2007, Cames, et al. 2010).

[313] Breastfeeding as a surrogate marker for HIV-positive status has been previously described by authors in various Sub-Saharan African settings (Moland, Sadoh, et al. 2009, de Paoli, et al. 2002, Blystad, et al. 2009, Eide, et al. 2006, Kasinga, et al 2008, Doherty, et al. 2006).

[314] The drivers of HIV-related stigma within African communities were discussed in detail in Chapter Five with reference to taking ART during pregnancy.

[315] Work from South Africa reveals that pregnant women and new mothers suspected of being HIV-positive may encounter mocking, social ostracism, abandonment, and physical violence (Doherty, et al 2006, Visser, et al. 2008). A study conducted by myself and colleagues in an East London HIV clinic in 2010 found that one in eight HIV-positive women had experienced intimate partner violence during

Although in the past HIV had many visible stigmata such as characteristic wasting or skin lesions, most people living with HIV with access to treatment will not be perceived as HIV-positive by those around them. In Goffman's terms they fall into the category of the "discreditable" ([1990] 1963: 14). Given the level of stigma and taboo surrounding HIV in many African communities, my participants were often under considerable pressure to "pass" (Ibid: 58) by presenting an HIV-negative social identity. This required careful management of information so as to keep their HIV-status hidden, such as hiding medication and making excuses for visits to the doctor. Many women described how public breastfeeding was the norm in their communities and that a woman who did not breastfeed her child would raise suspicions of HIV. Therefore the mother/bottle-fed infant dyad functions as a potent and visible stigma symbol "especially effective in drawing attention to a debasing identity discrepancy" (Ibid.: 59), constraining a woman's capacity to present an HIV-negative social identity.

The decision to avoid breastfeeding therefore encompasses much more than the minimisation of risk of HIV transmission to the baby. Transnational ideologies that valorise breastfeeding, structural barriers, a multiplicity of social meanings attached to breastfeeding and social pressure to conform to infant feeding norms place women in the unenviable position of balancing their needs with that of their child, demanding considerable resilience.

9.5 Feeding decisions have social consequences

Despite the difficulties women faced when avoiding breastfeeding, the majority of my participants managed to exclusively formula-feed their infants. However, the social organisation of meaning of different modalities of infant feeding meant that the decision to avoid breastfeeding had repercussions within the social domain.

Many women believed that breastfeeding was vital to bonding between mothers and their babies[316]. Consequently they worried that not breastfeeding would result in decreased attachment between themselves and their child. Breastfeeding was viewed as

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pregnancy, although the association with HIV disclosure was not specifically explored (Dhairyawan, et al. 2013).

[316] The belief that breastfeeding fosters emotional attachment between mother and child is widespread across many settings. See for example Hoffman's work in rural Burkina Faso (2009) and Buskens' description of HIV-positive mothers' attitudes towards breastfeeding in Namibia and Southern Africa (2007). A questionnaire study conducted among mothers in the US has also provided evidence of increased bonding through breastfeeding (Britton, et al. 2006).

a central route through which mothers could pass love on to their child[317]:

You transfer affection to the baby. It's like when partner goes on your breast. It's a kind of love you're transferring. You're showing your love.

(Bolade)

My participants saw breastfeeding as the only way to secure a unique link with their children and to ensure their children "knew" them. This was contrasted with formula feeding that "anybody at all can do for the baby". Breastfeeding is viewed in many communities as an important part of infant socialisation, transmitting maternal personal qualities (Mabilia 2005, Buskens et al. 2007, Hofmann et al. 2009), regulating infant behaviour (Seidel 2004) and strengthening kinship ties (Moland 2004). This was echoed by my participants who felt that a child who was not breastfed would be less likely to show respect or feel a sense of familial obligation as they grow older:

When a baby doesn't breastfeed, it doesn't listen to you. The baby that breastfeeds, you know, they have more love than the baby who doesn't [breast] feed.

(Fatima)

Breastfeeding has previously been explored through Mauss' concept of the gift (Shaw 2003, Mabilia 2005), emphasising breastfeeding as a socially embedded bodily practice. For Mauss the gift is as an important social interaction with three obligations; to give, to receive and to reciprocate ([2009] 1950). It may seem antithetical to frame breastfeeding within a Maussian notion of gift as it is commonly perceived as natural, spontaneous and non-contractual; the ultimate symbol of maternal "corporeal generosity" (Shaw 2003). However, for many of my participants there was a strong social expectation that they breastfeed their children, rendering it less a choice than a social obligation. There was an expectation that breast milk would be given in return for a child's love and respect, implying that breast milk had an active affective property[318]. Breastfeeding may be described as "generalised reciprocity" (Sahlins

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[317] See also Buskens' description of breastfeeding as forging a "lifelong 'love-link'" between mother and child in Southern Africa (2007), and Hoffman's ethnography of infant feeding in Burkina Faso in which she emphasises the importance of breastfeeding as a way of sharing love (2009).

[318] Also see Mabilia's ethnography of breastfeeding among the Gogo women in Tanzania where breastfeeding appears on the surface to be an act of unconditional maternal altruism. However, it exists within a system of social relations and meanings. For Mabilia's participants breastfeeding engenders an

1972), a form of supposed altruistic exchange, usually amongst kin, which carries an implicit acceptance of obligation that may be fulfilled in the future. Breastfeeding not only ties a child to its mother by love, reinforcing familial obligation, but it also shapes women's roles as mothers and structures relations with those around them[319]. As HIV-positive women exhorted by medical professionals to exclusively formula-feed, my participants were not only unable to assume the culturally-sanctioned role of the good breastfeeding mother, but they also found themselves isolated either because they were viewed with suspicion or because they withdrew from others for fear of disclosure and stigma. This reconfiguration of breastfeeding through the Maussian notion of the "gift" allows us to see that women living with HIV, unable to participate in the gift-exchange of breastfeeding, forgo important aspects of social interaction. Avoiding breastfeeding disrupts the bond between mother and infant, threatens her reputation and status within her community, and weakens ties between the mother and her wider social network.

Fear about disclosure of HIV status to friends, family and their wider social network was pervasive among my participants. I have already highlighted how the mother/bottle-fed infant dyad functions as a potent stigma symbol within many of my participants' communities, compromising women's ability to pass as HIV-negative. Furthermore not breastfeeding significantly impacted on women's self-esteem leading to feelings of inferiority or jealousy when encountering other mothers who were breastfeeding, who could otherwise have been an important part of their local support network. The desire to avoid uncomfortable questions and the disclosure of their HIV-positive status often resulted in varying degrees of social restriction in order to successfully manage information about themselves[320], such as the participant below who had started attending church less since the birth of her child and avoided environments where her feeding decisions may be probed:

My church members [...] they ask questions too much [...] so it is very hard 'cause they want to know everything. They have a mothers' room that you can go to with your baby

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emotional and social bond between mother and child as well as structuring relations between the mother and her wider community. Through breastfeeding Gogo women satisfy the expectations of those around them and secure their status within the community (2005).

[319] Moland's analysis of the cultural construction of breastfeeding among Chagga women in Tanzania highlights how breastfeeding strengthens women's status in their community (2004). Breastfeeding engenders respect and affords women social privileges during confinement such as more food and rest. In contrast women who cannot breastfeed are seen as "useless" and forego any benefits attached to nursing.

[320] Social isolation in an effort to prevent disclosure of HIV-status is a well-recognised aspect of HIV-positive motherhood (Desclaux, et al. 2009, Nuwagaba-Biribonwoha, et al. 2006, Blystad, et al. 2009, Cames, et al. 2010).

[...] but when I went to church I didn't want to go there. When everybody was there and feeding their baby [they ask] 'why you don't want to breast feed'?

(Grace)

This narrowing of the social sphere has previously been described by Green and Sobo (2000) in their study of the impact of HIV on identity and social relations. The threat HIV poses to someone socially is highly context-specific:

"Who one is, where one is, and who one is with largely determines one's perception and management of the social risk of being HIV positive, and dictate the extent to which HIV is incorporated publicly and privately into one's identity."

(Green et al. 2000)

My participants were migrant women living with HIV within communities where HIV remains highly stigmatised. Their lives were often complicated further by poverty, insecure immigration status and lack of partner support. I would argue that these women lack the social capital[321] to be able to incorporate HIV into their public identity and have little choice but to isolate themselves in an effort to conceal the potent stigma symbol of the mother/bottle-fed infant dyad[322].

9.6 Emerging resistance

Although the majority of my participants decided to avoid breastfeeding their baby, concerned about the risk of transmitting HIV to their baby, they were not wholly accepting of national guidance. According to Emily Martin, the consciousness of opposition and resistance can take many guises ranging from "lament" and "non-action" through to "resistance" and "rebellion" (Martin 1987: 184-189). Throughout this chapter I have foregrounded the considerable grief and distress experienced by my participants as a result of not breastfeeding their babies. It is important to view this

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[321] Here I am referring to Bourdieu's definition concept of social capital as the benefits people gain from their participation within social networks. Social capital is "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition" (Bourdieu 1986: 248)..

[322] Blystad and Moland (2009) have described how HIV-positive mothers in Tanzania and Ethiopia are unable to harness biosocial power from their HIV-positive status. Poverty and other modes of social marginalisation function as barriers in the formation of a positive and empowering identification with HIV as is seen within HIV activism. It is interesting to contrast these findings with those of Cecilia Van Hollen who found that HIV-positive mothers in Tamil Nadu were much less concerned about HIV disclosure (2011). She concludes that this is due to the low prevalence of HIV in Tamil Nadu and the low visibility of HIV, resulting in formula feeding not being a marker of HIV-positive status.

"lament" (Martin 1987: 184) as inchoate resistance as it suggests that women are not wholly accepting of the situation. Others manifested resistance in the form of expressed ambivalence about medical advice to abstain from breastfeeding. For some this centred around unresolved concerns about the long-term effects of not breastfeeding on their child's health:

They've [her children] got the energy. I mean there's no difference between them and any other children that are being breastfed [...] Well to me they don't look any different. But inside...I don't know what's going on inside.

(Esther)

For others their concern emanated from a mistrust of medical motives and a fear that professionals may be "lying". One woman framed this within a larger context of increasing and well-publicised public-sector cuts, suspicious that medical advice regarding infant feeding in HIV was driven by economics rather than patient need:

Look at delivery [...] why is it that they're not saying that when you're HIV you can just go straight to caesarean? Because they will be thinking of saving money 'Oh yes, we can try normal [delivery] because we could save some money.' [...] But when it's got nothing to do with them [the hospital] saving anything then they are like 'Don't do it at all.' [...] I am thinking if you were saving them money, say for example if it was compulsory for them to give formula, they would probably be encouraging women 'Okay, try to breastfeed up to this time' just to see if they can save money. But it's [formula feeding] not costing them anything and it's costing us. Obviously no one is thinking about you.

(Faith)

Another source of doubt for the participant above, and for others, was the clear discrepancy between guidance on infant feeding in the UK, and guidance issued by the WHO for resource-poor settings. In many resource poor settings, including many parts of Sub-Saharan Africa, HIV-positive mothers are advised to exclusively breastfeed their children as formula feeding is not is acceptable, feasible, affordable, sustainable and safe. Women had knowledge of this discrepancy in public health guidelines through their own research on the internet and through the strong links they maintained with their home countries where they often knew of HIV-positive women who had been advised to breastfeed. One woman's experience of the global disparities in infant feeding advice was more direct in that she had been advised to breastfeed on being diagnosed with HIV antenatally in Ghana, but on transferring her care to the UK to join her husband she had been informed that breastfeeding was risky and that she should exclusively formula-feed. My participants' location within diaspora gave them a unique vantage point of transnational disjunctures in public health policy, which sometimes led to confusion and frustration. Furthermore, this stark contrast between guidelines presents a challenge to the authoritative knowledge of biomedicine, laying bare its inherent inconsistencies.

During my fieldwork, only one woman disclosed to me that she was breastfeeding her child. I present her story here to provide a deeper understanding of the factors underlying an HIV-positive mother's decision to breastfeed against medical advice.

9.6.1 Ruth

Ruth, a Ugandan woman in her mid-twenties who migrated to the UK in 2001, had a six-month-old baby who was her second child. She had been diagnosed several years before and already had a son who was HIV-negative. Within months of delivering her son she had become pregnant again without planning to. She had a partner, also HIV-positive, who had been present at the birth of her youngest son but lived apart from her and provided little in the way of material and emotional support. Instead, Ruth lived with her mother (a church Pastor who was aware of her daughter's HIV status) and several other members of the extended family to whom Ruth had not disclosed. Ruth's social situation was precarious in that she did not have leave to remain in the UK and had no recourse to public funds. She occasionally managed to find some work informally as a hairdresser but she was essentially financially dependent on her family to provide for herself and her two young children. After her first pregnancy she had followed medical advice and had exclusively formula-fed her son. However, on the birth of her second son Ruth had made the decision to both breastfeed and formula-feed, having been satisfied that her HIV was well-controlled:

"my doctor was telling me everything was OK with my blood, that it's undetectable, so I said maybe I should just try. I thought it was my decision."

She had found not breastfeeding in her first pregnancy *"hard"*, whereas breastfeeding by contrast was *"easier, faster [...] and it's cheap"*. She also felt that this breastfeeding was better for her baby and that, as a mother, this was her decision to make. The confidence she had in this decision had been borne out by her baby's HIV-negative tests up until that point and the fact that he was thriving:

"at the end of the day, it was all good."

Ruth's story is illustrative as it condenses many of the themes introduced in this chapter and provides us with an insight into the drivers of "resistance"[323]. Again we see the limitations of the technical approach to risk that assumes that safety is paramount in the decisions people make about risk. Ruth's decision to breastfeed her child was underpinned by a complex set of factors including convenience, her belief in the nutritional superiority of breast milk, her understanding that having an undetectable viral load eliminated the risk of transmission[324] and a desire to have agency in decision-making about how to feed her child. However, it was Ruth's social marginalisation that loomed large in her narrative. As a single mother with insecure immigration status she was financially and socially dependent on her family, many of who were unaware of her HIV status. The decision to formula feed would have been met with suspicion, would have prompted questions or speculation about her HIV-status and would have been met with resistance in terms of financial assistance[325]. The structural violence enacted through British immigration law had set in motion a chain of dependency. As an HIV-positive woman with two young children and no citizenship rights, breastfeeding incurred less social risk to herself and her young family than formula feeding by allowing her to present an HIV-negative identity to the wider world. It was clear that the threat of poverty, homelessness and deportation were a greater risk to her child's health than the small biological risk of vertical transmission.

This narrative of resistance was hidden in that Ruth had not felt able to discuss her decision to breastfeed with her medical team "because they said I shouldn't do it", a striking example of the authoritative power of biomedicine[326]. The lack of an open discussion about the possibility of breastfeeding had led to Ruth being unaware of the

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[323] In Martin's discussion of oppositional consciousness she defines resistance as "refusing to accept a definition of oneself and saying so, refusing to act as requested or required" (1987: 187).

[324] As discussed earlier in the chapter, the risk of vertical transmission through breastfeeding is reduced through the use of maternal HAART but not eliminated.

[325] It is important to note that Ruth attended a clinic that was not set up to provide access to free formula and equipment to HIV-positive mothers.

[326] This concern was justified to some extent as when she finally informed her team, the revelation prompted a degree of anxiety in some team members who questioned Ruth's parenting and sought advice from local child protection services.

risks attached to mixed-feeding[327]. When she finally made the decision to disclose that she had been breastfeeding, she received support to wean safely and was offered further opportunities for her son to be HIV-tested.

9.7 Conclusions

The work presented in this chapter is the first in the UK to explore infant feeding decisions in women living with HIV, and is one of the first internationally to be conducted in a resource-rich setting. It exposes as false the dichotomy between infant feeding decisions in resource-poor settings and those in resource-rich settings, where it is often assumed that the decision to formula feed will be more straightforward and acceptable. Although the considerable infrastructure-related barriers to formula feeding faced by women in resource-poor settings may not be encountered in countries such as the UK, my participants were still subjected to economic constraints and dominant discourses that valorise breastfeeding. Where this study differs from those conducted in other resource-poor settings is in its focus on women within the African diaspora. My participants' location within diaspora gave them an acute awareness of transnational disjunctures in public health policy on infant feeding in the context of HV. Furthermore, the poverty and lack of citizenship rights that often accompany migration, forced some women into economic dependency on those around them, presenting a further challenge to their ability to adhere to their decision to formula feed.

All but one woman I interviewed postnatally avoided breastfeeding their babies, however this decision came at great personal and social cost. Rather than being decisions made by an individual solely to ensure safety (in this context to eliminate the risk of vertical transmission), decisions on how to feed their babies were highly relational in nature and were subjected to a range of competing concerns. The consequences of not breastfeeding manifested clearly within the social domain, resulting in anxieties about bonding with their child, a restriction in the social sphere in order to avoid HIV disclosure, and the spoiling of a woman's identity as a good mother with consequent loss of status and self-esteem. Given the challenges that avoiding breastfeeding presents to migrant African women living with HIV, it is hardly surprising that there is emerging opposition on a spectrum from lament to overt resistance.

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[327] Earlier in this chapter I described how mixed-feeding (that is breastfeeding in combination with other sources of food including formula) carries a greater risk of vertical transmission than either exclusive breast or formula feeding.

Despite the significant challenges, women continued to prioritise the needs of their child and avoided breastfeeding. However, it is important to realise that the decision to breastfeed in the context of HIV is not an irrational one, but one based on minimising other risks, and is one that also is centred upon a mother doing what she thinks is best for her child. As professionals we need to extend our notion of risk, which is informed by public health and the need to minimise vertical transmission, and appreciate risk in its multidimensional form.

Key points

- The majority of HIV-positive women adhere to current UK guidelines to formula feed exclusively.

- Key difficulties encountered by women in avoiding breastfeeding are cultural notions of the superiority of breastfeeding, fears of disclosure of HIV status, financial cost and apparent transnational disjunctures in public health policy.

- The decision to abstain from breastfeeding comes at significant personal and social cost to women and requires considerable support in order to create an enabling environment.

- Some HIV-positive women will choose to breastfeed despite medical advice. These decisions are rarely irrational and are also centred on the health and wellbeing of their child. Mothers who choose to breastfeed will require particular support in order to be able to do so safely and without judgment.

10

Discussion

Summary

In this, the penultimate chapter of my thesis I present a synthesis of my quantitative and qualitative findings with reference to the overarching research question as well as the specific questions I posed in Chapter One. I highlight how my research has generated new knowledge in key areas. I conclude with a discussion of the strengths and limitations of my methodological approach in this thesis.

10.1 Engagement with HIV services during and after pregnancy

The overarching research question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? This question arose because of the increasing number of pregnancies reported in women living with HIV in the UK, the overwhelming majority of whom were born in Sub-Saharan Africa. It is a response to the dearth of literature on HIV and pregnancy that specifically engages with maternal-focused outcomes and lived experiences of women. The thesis focuses on the relationship between outcomes and experiences of pregnancy among HIV-positive women in the UK, and maternal ethnicity, African region of origin and duration of residence in the UK. To the best of my knowledge, this is the first time such research has been conducted in the UK.

To answer the overarching research question (how do African women engage with HIV services and interventions during and after pregnancy?), I posed three specific questions in Chapter One:

1. Are maternal ethnicity, African region of birth and duration of residence in the UK *associated* with:
    a. Not receiving ART during pregnancy
    b. Detectable maternal HIV viral load at delivery

    c. Vertical transmission of HIV

    d. Late antenatal booking

    e. Loss to follow-up from HIV care in the year after pregnancy

2. What are the *mechanisms* underlying associations between clinical and service outcomes, and maternal ethnicity, African region of birth and duration of residence in the UK?

3. What are the *experiences* of African women living with HIV during and after pregnancy?

I will now synthesise key findings from my research to answer these questions.

10.2 Research question one

My first question was: are maternal ethnicity, African region of birth and duration of residence in the UK associated with: not receiving ART during pregnancy; detectable maternal HIV viral load at delivery; vertical transmission of HIV; late antenatal booking; and loss to follow-up from HIV care in the year after pregnancy.

10.2.1 Trends in pregnancies among women living with HIV

In Chapter Four I showed that the number of reported pregnancies in women living with HIV in the UK has increased dramatically since 1990. This is mainly a consequence of the widespread availability of HAART affording greater reproductive opportunity, but also the increased number of diagnoses of HIV in pregnancy as a result of the introduction of routine antenatal screening for HIV from 2000 and the increasing number of women, particularly from Sub-Saharan Africa, being diagnosed with HIV in the UK. The number of women reported as pregnant stabilised at approximately 1400 per year between 2006 and 2010[328]. The overwhelming majority of HIV-positive women reported as pregnant between 1990 and 2010 were African. The proportion of women reported as pregnant to the NSHPC who were African increased between 1990 and 2006 and then levelled off, partly reflecting the plateauing of immigration to the UK (including from Commonwealth nations) in recent years (Migration Observatory 2011). In 2010, 1351 pregnancies were reported in HIV-positive women in the UK.

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[328] This is largely a result of a decrease in numbers of women newly diagnosed with HIV during pregnancy in recent years (Byrne, et al. 2013).

The largest number of pregnancies in HIV-positive women was reported in London; nearly all were in African women. Outside London the proportion of pregnancies that were in African women was lower, although still high.

Chapter Four explored, for the first time, pregnancy in different groups of HIV-positive African women in the UK from an epidemiological perspective. The greatest proportion of pregnancies in African women was in those born in Eastern Africa. However, the proportion of pregnancies in women from Eastern Africa declined between 1990 and 2010, whilst the proportion in those from Western Africa (predominantly Nigeria) increased over the same time period. This diversification in terms of African region of birth was also seen in the general adult HIV-positive population in the UK between 2001 and 2010 (Meaghan Kall, Public Health England, personal communication, 25 June 2012) and reflects underlying migration patterns to the England and Wales[329].

10.2.2 Key outcomes

Almost all women in the analysis of NSHPC data presented in Chapter Five received ART during their pregnancy, in keeping with rates of ART uptake reported in the UK and Ireland as a whole ((Townsend et al. 2008b) and in Western Europe more widely (Mayaux et al. 2003, Bailey et al. 2011). Using imputed viral load data I found rates of virological suppression of approximately 80%, similar to findings reported by other authors (Patel et al. 2007, Baroncelli et al. 2009, Burgard et al. 2010, Katz et al. 2010, Joao et al. 2012). In the analysis in Chapter Five the rate of vertical transmission of HIV was low at just over 1%, which is similar to rates reported in other studies, including a previous analysis of NSHPC data (Townsend et al. 2008a, Warszawski et al. 2008, Baroncelli et al. 2009, European Collaborative Study 2010, von Linstow et al. 2010).

In Chapter Seven I found that nearly one in two HIV-positive women booked late for antenatal care at thirteen weeks' gestation or beyond. My analysis is one of the largest studies to date to explore antenatal booking in HIV-positive women, and is the only one to focus on this in detail. Only two previous studies, one from the UK (Parisaei et al. 2007) and the other from France (Jasseron et al. 2011) have looked at antenatal booking

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[329] According to the most recent Census there has been a greater increase in the number of residents in England and Wales who were born in Western and Central Africa compared to the increase in those born in Southern and Eastern Africa, as described in Chapter Four (115-116).

in women living with HIV, both reporting much lower rates. However, these studies both used a different definition of late booking from my analysis (beyond twenty weeks' gestation).

Finally, I explored loss to follow-up from HIV care in the year after pregnancy using matched data from NSHPC and SOPHID. The work I presented in Chapter Eight is the largest study to date to explore loss to follow-up from HIV services after pregnancy, and the first to use national surveillance datasets. As such, it makes an important contribution to the broader literature that focuses on retention in HIV care and the treatment cascade in people living with HIV. In this analysis I have shown that one in eight women do not return for HIV care in the year after their pregnancy. This is consistent with data in the overall HIV-positive population in the UK (Rice et al. 2011) and is lower than rates reported in previous studies of loss to follow-up postnatally (Saulsbury et al. 2004, Lemly et al. 2007), both of which were smaller and used a definition of loss to follow-up that differed from mine.

10.2.3 The association between maternal ethnicity, African region of birth and duration of residence in the UK, and key outcomes

I now return to one of the key questions posed in this thesis: are maternal ethnicity, African region of birth and duration of residence in the UK (which I will refer to in this chapter as "migration-related factors") associated with key outcomes during and after pregnancy? It is important to note from the outset that there has been almost no work to date looking at either maternal region of birth or duration of residence in the UK among migrant groups with regards to HIV and pregnancy, with the majority of work to date looking at either ethnicity or race (if conducted in the United States) alone.

The key clinical and service-related outcomes I examined in Chapters Five and Seven were: not receiving ART in pregnancy, detectable maternal viral load at delivery, vertical transmission of HIV, late antenatal booking and loss to follow-up one year after pregnancy. Overall I found no consistent association between any of the three migration-related factors and key outcomes. Rather, the effect of migration-related factors varied according to outcome.

Not receiving ART in pregnancy

In Chapter Five I found no evidence of an association between African ethnicity and *not* receiving ART during pregnancy[330]. A new finding from my analysis was the disparity in receiving ART during pregnancy between different groups of African women. However, it is important to keep in mind that the overwhelming majority of women in all these groups *did* receive ART in pregnancy. Women from Western Africa were more likely than Eastern African women *not* to receive ART in pregnancy, with Western African women, as well those from Middle Africa, also more likely to have declined treatment. In addition, I have shown that African women who had arrived in the UK after conception were more likely *not* to receive ART in pregnancy than those who had been in the UK for four years or more.

Detectable maternal HIV viral load at delivery

Very few studies to date have looked at the impact of ethnicity, or indeed other migration-related factors, on maternal viral load at delivery. Previous work has shown that migrant women (predominantly African) were as likely as non-migrant women to suppress virologically by delivery (Floridia et al. 2010, Izzo et al. 2011). The findings presented in Chapter Five support this in that I also found no association between either ethnicity or African region of birth, and detectable maternal viral load at delivery. A new finding is that African women who had arrived in the UK after conception had poorer outcomes, being at greatest risk of having a detectable viral load at delivery.

Vertical transmission of HIV

In Chapter Five I found no association between either ethnicity or African region of birth and vertical transmission, in keeping with findings reported by other authors including a previous analysis of NSHPC data (Jasseron et al. 2008, Townsend et al. 2008a). The rate of vertical transmission was elevated in pregnancies among women who had arrived in the UK after conception compared to those who had been in the UK for four or more years[331].

Late antenatal booking

The work I present in Chapter Seven is the first study in the UK to explore in detail the

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[330] Although one American study has demonstrated decreased uptake of ART in pregnancy in Black women compared to White women (Abatemarco, et al. 2008), my findings are consistent with those from a French cohort showing no association between Sub-Saharan geographical origin and uptake of ART in pregnancy (Mayaux, et al. 2003).

[331] This was no longer statistically significant after adjusting for duration of ART, suggesting that the association between shorter duration of residence and vertical transmission was largely due to a shorter duration of treatment.

association between migration-related factors and late antenatal booking in women living with HIV. I have found an association between late booking and ethnicity, with African women approximately twice as likely to book late as white British women[332], which is in keeping with previous findings from a French study (Jasseron et al., 2008). There was no evidence of an association between late antenatal booking and either African region of birth or duration of residence in the UK.

Loss to follow-up after pregnancy

Finally in Chapter Eight I explored maternal loss to follow-up one year after pregnancy. To date, all research on retention in HIV care *postnatally* among HIV-positive women has been conducted in Sub-Saharan Africa and has not explored the impact of migration-related factors. The work I present in this thesis is the first from a resource-rich setting to explore retention in care after pregnancy on a large scale. To the best of my knowledge it is also the only study to date, regardless of pregnancy, to explore the heterogeneity between different groups of Africans with regards to retention in HIV care, identifying groups that may require particular support to engage with and access services.

I have shown that African women are more likely than white British women *not* to attend for HIV care in the year after pregnancy. This fits with findings in the overall HIV-positive population in the UK showing an association between Black African ethnicity and lower retention in care (Gerver et al. 2010, Rice et al. 2011, Clay 2013)[333]. Looking at African women in greater detail, I have shown that those from Western and Southern Africa were at greater risk of being lost to follow-up than those from Eastern Africa. Furthermore, women who had arrived in the UK after conception were more likely not to return for follow-up in the year after pregnancy than those who had been resident for four or more years.

In summary, I have explored the association between migration-related factors and a range of clinical and service-related outcomes in pregnancy (see table 10.1). Key findings include the association between African ethnicity and both late antenatal booking and loss to follow-up after pregnancy; and the association between African region of birth and the receipt of ART in pregnancy and loss to follow-up after

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[332] This reflects the well-documented association between ethnicity, migration and late booking seen among pregnant women in general as summarised in Chapter Two.

[333] It also echoes work from other parts of Europe and the US, which show poorer retention in care for those of non-white ethnicity, as summarised in Chapter Two.

pregnancy. A striking finding is the consistent association between arrival in the UK after conception and not receiving ART during pregnancy, detectable viral load at delivery, vertical transmission and loss to follow-up after pregnancy. This is the first time that this particular group of women has been identified as vulnerable in analyses of observational data on HIV in pregnancy.

Table 10.1: Summary table of association between maternal ethnicity, African region of birth and duration of residence in the UK, and key outcomes (Chapters Five, Seven and Eight)

	African ethnicity	African region of birth	Arrival in the UK after conception
Not receiving ART during pregnancy	x	✓	✓
Detectable viral load at delivery	x	x	✓
Vertical transmission	x	x	✓
Late antenatal booking	✓	x	N/A
Loss to follow up after pregnancy	✓	✓	✓

10.3 Research question two

My second question was: what are the mechanisms underlying the associations between clinical and service outcomes, and maternal ethnicity, African region of birth and duration of residence in the UK? I explored this question using qualitative research methods. My work comes from an anthropological tradition and engages ethnographically with previously unexplored areas such as how conditions of diaspora influence engagement with services, the role of Pentecostal churches in shaping attitudes towards illness, and the social construction of risk. Furthermore, by deploying a conceptual framework of structural violence, I have situated my findings within a broader global literature on how unequal social arrangements come to be embodied by people living with HIV (Farmer 2004, Fassin 2007).

In this section I touch upon themes that contextualise the key quantitative findings summarised in section 10.2.

10.3.1 Women engaging in care

As shown in section 10.2.2, the findings from the epidemiological analyses are largely reassuring with high rates of receipt of ART in pregnancy, good levels of virological suppression, low rates of vertical transmission and the majority of women being retained in HIV care after pregnancy. This suggests that women engage well with healthcare both during and after pregnancy. This was borne out by findings from my ethnographic fieldwork.

Women valued their HIV antenatal care highly, describing close relationships with a core group of professionals that they saw regularly through their pregnancy. This fostered trust in the healthcare system as a whole and it gave women the confidence to return. An important aspect of the care they received from their multidisciplinary HIV antenatal team was the fact that it was often situated within the context of day-to-day life as a migrant in London with support extending beyond the medical domain to address structural constraints through financial support and assistance with immigration matters.

In Chapters Five, Seven and Eight I framed this engagement with healthcare professionals within the broader frame of African HIV-positive women’s lives and Mol’s “logic of care” (2008). Mol contrasts the logic of care with the “logic of choice” which appears to be the dominant paradigm in contemporary healthcare delivery. Healthcare settings are increasingly subjected to market forces and choice, with people suffering ill health transformed from patients to consumers (Ibid.). Underlying the principle of choice is the assumption that choices are made by autonomous individuals through the careful weighing up of advantages and disadvantages at a specific moment in time (Ibid.). The logic of choice dictates that if a patient does not adhere to a certain intervention it is their individual responsibility. The logic of care, on the other hand, views decision-making as embedded within a broader field of action and requiring constant recalibrating. The implementation of the Health and Social Care Act 2012[334],

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[334] The Health and Social Care Act 2012 was an Act of Parliament implemented in the UK in April 2013, to widespread concern from the Royal Medical Colleges, precipitating the most extensive restructuring of the NHS since its inception. Key underlying principles enshrined by the Act include opening up the NHS

with its enshrinement of patient choice as a driver of improvement of NHS care, therefore raises concern as it may lack core values inherent in the “logic of care” that have been instrumental in engaging the women in this study in HIV services during and after pregnancy.

For many women in my ethnographic fieldwork biomedicine was not a technological innovation. The majority were from urbanised elite backgrounds in Africa and had extensive experience of biomedicine in their home countries. Biomedicine has successfully penetrated health settings internationally and has widespread prestige and purchase. Inspired by Appadurai’s concept of *–scapes* (1996), I have deployed the neologism *healthscape* to capture the transnational flow of medical knowledge and technologies and their specific local articulations. African women living with HIV in the UK exist within a global healthscape where biomedicine is highly visible and popular. Seeking medical care for pregnancy and HIV was therefore not culturally alien.

However, their vantage point within diaspora gave them an acute sense of disjunctures within the healthscape as it manifests in the UK and in Sub-Saharan Africa. For some women, the knowledge that they could access services and interventions that may not be readily available in their home countries served as a motivating force to engage with HIV care.

Finally, engagement with services and interventions, although often requiring considerable effort on the part of women, reduced the risk of vertical transmission and afforded women longer survival thus enabling them to achieve motherhood, a core component of their identities as women, whilst safeguarding their children’s health.

10.3.2 Extending notions of risk to understand disparities

Although the majority of women appeared to engage well with different aspects of care in analyses of NSHPC data, disparities in outcomes by migration-related factors were identified as summarised in 10.2.3. The impact of ethnicity, African region of origin and duration of residence in the UK was complex and shifted according to which outcomes were considered. However women who had arrived in the UK after

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to the forces of competition and choice in order to drive quality improvement and value for money. See "Factsheet C4" on choice and competition in the Act, published by the Department of Health and available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138269/C4.-Factsheet-Choice-and-competition-270412.pdf (accessed 23 September 2013).

conception (many of who would have had insecure immigration status), and to a lesser extent women from Western Africa, emerged as groups who appeared to have poorer engagement with HIV care during and after pregnancy.

I will now focus upon women from Western Africa and women with insecure immigration status, in order to summarise the challenges they may encounter in engaging with HIV services and interventions. It is important to note that the challenges I describe here faced by Western African women and women with insecure immigration status are not confined to these groups and may extend not only to other groups of African women but also to HIV-positive women in general. However I have chosen to focus upon these two groups as they foreground many salient points from my ethnographic research.

Western African women

Women from Western Africa were more likely *not* to receive ART during pregnancy and were also more likely to have declined it. Furthermore, Western African women (along with those from Southern Africa[335]) were also more likely to be lost to follow-up from HIV care in the year after pregnancy. This was borne out by the experiences of healthcare professionals who identified women from Western Africa as being the hardest group of women to engage in care.

Professionals often attributed poorer engagement with HIV care to the predominance of Pentecostalism within West African communities and widespread beliefs in divine healing. However, this was not supported by findings from my ethnographic fieldwork. Beliefs in divine healing are situated in a wider cosmological framework in which all types of misfortune are addressed through spiritual warfare. However, seeking a spiritual solution to misfortune does not preclude other approaches. My work reveals that women draw upon their Pentecostal faith *alongside* biomedicine, in a pragmatic quest to manage life with HIV. Pentecostalism not only offers succour in the form of material assistance and a sense of collectivity within a church, but is also an important resource in fostering hope and self-efficacy.

A more important barrier to engaging with HIV care is likely to be the particularly high level of HIV-related stigma within West African communities cited by a number of my

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[335] I was not able to recruit any participants from Southern Africa to interview and it is therefore difficult for me to comment further on increased rates of loss to follow-up one year after pregnancy in this group.

participants[336]. Fear of disclosure of HIV status and consequent stigma and discrimination were common among Western African women. Attendance for antenatal care was seen as a normal part of pregnancy. However returning for care *after* pregnancy, especially in a clinic that was known to provide HIV care, risks compromising women's ability to pass as HIV-negative, as does taking antiretroviral medication.

HIV-related stigma was a common theme in my interviews with pregnant women *regardless* of their region of birth. Although experiences and fears of stigma and discrimination are shared by many people living with HIV, I suggest that they may be more pronounced among African women in the diaspora. A range of structurally violent factors including poverty, pervasive HIV-related stigma within migrant African communities, insecure immigration status and subsequent circumspection towards institutions, material dependency on partners and family in the absence of UK citizenship rights and experiences of intimate partner violence, all intersect to constrain the capacity of women to address HIV-related stigma. Furthermore, the combination of these pernicious social forces may also make women more vulnerable to experiencing stigma and discrimination both within and outside of healthcare settings, with a consequent impact on the willingness of *some* to engage with care[337].

Women with insecure immigration status

A vulnerable group of women identified in the quantitative analyses were those who had arrived in the UK after conception, many of whom are likely to have had insecure immigration status[338]. For many women without secure immigration status, destitution and food insecurity were part of everyday life, with many unable to work due to restrictive immigration policies. Their lives were dominated by their immigration status and the consequent structural violence that this brought in the form of poverty and housing crises. In this context of chronic and extreme material insecurity, HIV and healthcare may fall lower and lower in the hierarchy of needs (Maslow 1943). Some women were forced to depend on friends, family and sometimes violent partners, setting in motion a chain of further vulnerability. Material dependency on family and partners

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[336] Although HIV-related stigma and discrimination is a common experience for many people living with HIV, I suggest that they may be heightened within Western African communities where the epidemic is less established and HIV is historically less visible. See Chapter Five (164) for a discussion of regional variations in HIV-related stigma in Sub-Saharan Africa.

[337] It is important to emphasise here that the majority of women engage well with HIV services and interventions during and after pregnancy.

[338] The NSHPC does not collect data on immigration status.

often precluded HIV disclosure, resulting in anxieties about being seen to attend for HIV care and to take ART.

Engagement in care was further compromised for *some* women by fears of being reported to immigration authorities and repeated demands for payment by hospitals, in contravention of Department of Health guidelines. Furthermore, for the entire duration of my fieldwork anyone without secure immigration status in the UK was liable to incur charges for HIV treatment outside of pregnancy, posing an even greater barrier to treatment for an already marginalised and poverty-stricken group of people.

The global financial crisis has ushered in a range of biting austerity measures across Europe. In 2009 the World Health Organisation warned of the impact this would have on health and social care, stating that the world's poorest and most marginalised populations would be most affected (World Health Organisation 2009a). During my fieldwork between 2010 and 2011 the impact of austerity measures and cuts to welfare spending was evident in the increased workload placed on Body & Soul and similar voluntary sector organisations, and in the references made by some participants to government cuts as a possible reason for negative experiences of healthcare.

As the financial crisis has deepened there has been a rise in xenophobic violence across Europe (Chauvin et al. 2013) and a resurgence in nationalist politics and far right movements. In May of this year, the UK Independence Party (UKip), a right wing populist political party characterised by Eurosceptism and a tough line on immigration, won over 25% of the share of the vote in English local elections (Watt 2013). This lurch to the right in British politics has resulted in the current government setting out policies that seek to curb the rights of migrants to social welfare and healthcare[339] with the current Health Secretary vowing to restrict access to healthcare to all but those with permanent UK residency (Dominiczak 2013). This has been accompanied by an increasingly robust and divisive policy approach to immigration perhaps best exemplified by the UK Border Agency's recent deployment of vans displaying large adverts exhorting illegal immigrants to "Go home or face arrest"[340].

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[339] See the transcript of the Queen's Speech 2013 on the legislative programme for government available at https://www.gov.uk/government/speeches/the-queens-speech-2013.

[340] This controversial pilot scheme was introduced in July 2013 in six boroughs of London known for their ethnic diversity (see http://www.ukba.homeoffice.gov.uk/sitecontent/newsarticles/2013/july/50-returns-pilot, accessed 23 September 2013). It has been widely criticised by civil liberties organisations as it has been viewed as operating racial profiling and deploying rhetoric reminiscent of fascist slogans in the 1970s (see http://www.liberty-human-rights.org.uk/media/press/2013/press-advisory-stirring-up-tension-and-division-in-the-uk-illegally-home-office-think-again.php, accessed 23 September 2013).

Measures such as these that target some of the most vulnerable and marginalised in our society are structurally violent acts, rendering the lives of migrants “bare” (Agamben 1998). The current political and economic climate raises concerns about whether HIV-positive women without secure immigration status will be able to continue to overcome their fears and anxiety, as well as growing institutional barriers, to access the care they need to maintain their own health as well as that of their newborn babies.

10.4 Research question three

My third question was: how do African women living with HIV experience HIV services and interventions during and after pregnancy? Here I summarise important experiences shared by many African women that emerged from my ethnographic fieldwork in relation to two key themes: maternity care and infant feeding.

10.4.1 Negative experiences of maternity care

Only one other recent study from the UK has engaged with women’s experiences of maternity services in the context of HIV (Kelly et al. 2012b). This small study reported negative experiences of maternity services mainly as a result of lack of empathy. Although most women in my study described the care they had received *antenatally* in positive terms, eight of the fifteen women I interviewed *postnatally* described negative experiences of maternity care during labour and immediately afterwards, their experiences ranging from neglect to frank discrimination (Chapter Seven). Some of my participants described episodes of overt discrimination as a result of their HIV status whereas others felt that the poor treatment they were experiencing was a result of their HIV-status. Furthermore, lack of social support, poverty and anxieties about their immigration status rendered some of them more vulnerable to discrimination within maternity services and constrained their agency to address it when it occurred, highlighting again how stigma articulates with other modes of inequality in a synergistic fashion to create conditions of vulnerability (Castro et al. 2005).

10.4.2 Infant feeding decisions

The work I present in Chapter Nine is the first in the UK to explore infant feeding among HIV-positive women in the UK, specifically framing the analysis within cultural theories of risk. It provides an entry point into the experiences of infant feeding among women living with HIV in resource-rich settings, an area that has previously been overlooked.

All but one of the women adhered to current UK guidelines to abstain from breastfeeding but this decision was fraught and complex, and deeply embedded within the social domain. Firstly, on an operational level, the provision of free formula milk and sterilising equipment was not guaranteed across all NHS sites and placed women who were already destitute, and sometimes had no recourse to public funds, in the intolerable situation of not knowing how they would be able to feed their newborn babies. Furthermore, women were subjected to transnational ideologies that valorise breastfeeding, which can make the decision to abstain particularly painful. Their decision was further complicated by the conditions of diaspora in that they were well aware of the disjuncture between guidance in the UK, and guidance in African countries that promotes exclusive breastfeeding in the context of HIV.

Formula feeding came at significant personal cost with many women experiencing anxieties about bonding and the health of their child and an acute sense of personal loss of the joys of breastfeeding. It had also had significant repercussions in the social domain as the mother/bottle-fed child dyad functioned as a visible stigma symbol compromising a woman’s ability to present an HIV-negative self, often resulting in withdrawal from the social sphere to preserve confidentiality.

10.5 Strengths and limitations of the study

10.5.1 Quantitative methods

The quantitative phase of this study was primarily based on data from the National Study of HIV in Pregnancy and Childhood, the UK and Ireland’s comprehensive surveillance programme for HIV in pregnancy and childhood, which has been running since 1986. The great strength of the NSHPC is that it has national coverage and all women with diagnosed HIV-infection are eligible for inclusion[341].

One important limitation of using large surveillance datasets is that its primary objective is to provide a comprehensive overview of disease epidemiology, rather than to address specific research questions. In order to maximise response rates and to facilitate data-management there are necessary constraints on the amount of data that can be collected. There is no information on potentially important confounders such as immigration status, socioeconomic status, adherence to ART, disclosure of HIV status and maternal smoking history. There may therefore be some residual confounding in my analyses.

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[341] See Chapter Three (61) for a discussion of the strengths of the NSHPC study design.

Data were missing for many variables inevitably. However on the whole this was minimal and for some variables was likely to be missing completely at random[342] i.e. a result of someone simply overlooking a question on the notification form.

10.5.2 Qualitative methods

The fieldwork was conducted entirely in London, which has the greatest concentration of HIV clinical and support services. However, it is reasonable to assume that challenges encountered by women in London, where support is likely to be greater than elsewhere in the UK, will be experienced by women elsewhere.

The findings presented in this thesis should be interpreted with caution, as they may not reflect the experiences of women who do not engage well with HIV care either during or after pregnancy. All women, except one, were recruited from NHS sites and were therefore attending for care. Women who were poorly engaged in care were unlikely to consent to participate in a study, and those with complex pregnancies (either socially or medically) were often not approached by healthcare providers as understandably their social and medical needs were prioritised. Furthermore, I was unable to interview some women postnatally and therefore may not have captured the experiences of women who disengage from services after pregnancy.

In order to explore the role of Pentecostalism in the lives of migrant Africans I conducted six weeks of fieldwork. This was brief by necessity given the time constraints of a three-year mixed-methods PhD and has particular limitations when compared with the prolonged periods of immersion typical of most anthropological research. A longer period of ethnographic fieldwork would have resulted in a deeper understanding of TCPM and may have given me more opportunity to encounter members and discuss HIV specifically. It may have also resulted in greater access to members of the clergy. Discussions with anthropologists conducting fieldwork within other Pentecostal churches in the UK revealed that older and more established churches were often more open to researchers. However, on reflection I feel that TCPM, a rapidly growing church attracting a large following often at the expense of the more established churches, is precisely where work such as mine needs to be located.

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[342] The mechanisms and effects of missing data on my quantitative analyses are discussed in detail in Chapter Three (73-76).

10.6 Reflections on mixing methods

In this thesis I have combined epidemiological and anthropological methods. Although the use of mixed methods in health research is growing (O'Cathain et al. 2007), the combination of anthropology and epidemiology remains rare (Béhague et al. 2008). Rather than conducting primary data collection in my quantitative phase, I undertook secondary analysis using an existing national surveillance dataset. There were therefore disjunctures between the quantitative and qualitative phases. I could not shape the quantitative data collection to reflect areas of interest that were explored in the qualitative phase such as the impact of Pentecostal Christian faith on clinical and service-related outcomes. However, not only was this approach time efficient within the constraints of a three-year PhD, but also the size and coverage of the NSHPC dataset afforded me statistical power and the ability to generalise my quantitative findings that I would not have had had I conducted my own primary quantitative research.

Certain conditions enabled the quantitative and qualitative data to be integrated, namely that both the NSHPC data and data from qualitative interviews were obtained from women attending for NHS care in the UK. Furthermore, in view of the coverage and high case ascertainment within the NSHPC it is likely that the women I interviewed were already included in NSHPC data or would be in the future. I therefore feel confident in extrapolating findings across both sources of data. The disjuncture in datasets and type of data has presented difficulties at times in terms of achieving an integrated analysis and presentation (Bryman 2007). However, despite these challenges I have been able to integrate quantitative and qualitative findings in three of the six empirical chapters in this thesis, and in this discussion chapter.

The overarching research question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy? This encompasses questions about clinical and service-related outcomes as well as personal experiences and demands a range of research methods. The combination of quantitative and qualitative methods has not only allowed me to get closer to a multidimensional account of pregnancy in migrant African women in the UK, but it has also allowed me to harness the strengths of different methodologies. The quantitative data have provided a national view and generalisable results, and have also guided me in terms of my sampling and analysis in the qualitative phase. The qualitative data have added texture and context, allowing me to explore the mechanisms that underlie disparities in clinical and service-related outcomes. Each approach generated insights that would not been possible without the other, such as women's accounts of discrimination within maternity services and associations between ethnicity and loss to follow-up after pregnancy. The mixed-methods approach in this study has therefore been instrumental in allowing me to answer my overarching research question.

10.7 Conclusions

The mixed methodological approach used in this study has provided a multidimensional account of the engagement with HIV services and interventions by HIV-positive African women in the UK during and after pregnancy. My overarching research question was: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy?

The findings from this study are largely reassuring in that they suggest that African women engage well with HIV care during pregnancy, and are motivated to return for their own care following the end of their pregnancy. This is mainly due to their motivation to safeguard the health of their babies, and also to relationships that they build with their HIV antenatal team that fosters trust medical in systems. However, some women reported negative experiences, particularly with regards to poor maternity care at the time of delivery and difficulties in abstaining from breastfeeding.

I did identify disparities in engagement in care. The association between maternal ethnicity, African region of birth and duration of residence in the UK with key outcomes is complex, although women who arrive in the UK after conception emerged as a vulnerable group in my analysis, as did Western African women to a lesser extent. Pentecostal beliefs in divine healing, although cited by professionals as a potential barrier to HIV care, do not appear to prevent the majority of African women from engaging with HIV services and interventions. Instead, a complex constellation of cultural and structural factors such as stigma, concerns regarding disclosure of HIV status, poverty and lack of UK citizenship rights present a greater challenge to engagement with care, and may be felt disproportionately by certain groups of African women.

11

Final reflections

Summary

The overarching research question posed in this thesis emerged from my experiences as an HIV physician working with pregnant migrant African women living with HIV and a desire to improve delivery of care to this group of patients. In this final chapter I suggest an agenda for further research and make key recommendations for the collection of surveillance data, the delivery of clinical services, and the development of wider public policy. In the fullness of time I hope that these recommendations lead to an improvement in the care of pregnant African women living with HIV in the UK.

11.1 Overview of findings

The overarching research question posed in this thesis is: how do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy?

Except for the high proportion of women who booked for antenatal care beyond the current recommended timeframe, the findings from my analysis of NHSPC data in this thesis are very reassuring. Almost all women in the UK diagnosed with HIV took ART in pregnancy, the vast majority achieving virological suppression by delivery with extremely low rates of vertical transmission, and the overwhelming majority returned to HIV services after their pregnancy. This suggests that women are well engaged with HIV care during pregnancy, and are motivated to return for their own care following the end of their pregnancy. Key motivating factors in women’s engagement with care were the importance of attaining normality through motherhood, safeguarding their newborn babies’ health, and relationships with their HIV antenatal team that fostered trust and confidence.

Negative experiences of health services and interventions were reported by a number of women, the most important being poor care within maternity services around the time of delivery and difficulties encountered in abstaining from breastfeeding. One of the most vulnerable groups identified in my analyses were women who had arrived in the UK after conception, many of whom were likely to have had insecure immigration status. For some of these women, the structurally violent and intersecting forces of poverty, economic dependence, stigma and lack of citizenship rights appeared to constrain their capacity to engage with HIV care during and after pregnancy.

11.2 Future work

The work presented in this thesis highlights important avenues for future research.

The first area encompasses statistical approaches to the NSHPC dataset. Due to the complexities of the NSHPC dataset structure I was unable to use emergent imputation methods to address the large amount of missing data on duration of residence data. Software now exists that could make this computationally possible and it would be useful to explore the feasibility and effects of imputing values in NSHPC analyses using variables with large amounts of missing data.

A recommendation for future analysis of HIV epidemiological datasets more broadly, is for an awareness of the heterogeneity within broad ethnicity categories and the potential to identify differences through disaggregation. One example of this is the analysis of loss to follow-up after pregnancy presented in Chapter Eight, which revealed disparities *between* different groups of African women. It would be valuable to explore whether these associations are replicated in the overall adult HIV-positive population by disaggregating data on Black Africans, as it may allow us to identify groups that require particular support in engaging with HIV care.

Moving on to specific analyses, I have identified late antenatal booking as a common feature of pregnancy in HIV-positive women, especially those from Africa. Further studies specifically comparing initiation of antenatal care in HIV-negative and HIV-positive women would help clarify whether late booking is specifically related to HIV itself. As the number of reports with available data on antenatal booking increases, it will be possible to conduct further analyses exploring both later cut-off points for late antenatal booking, and the associations between late booking and clinical outcomes. I also suggest that further qualitative work be undertaken to specifically explore late antenatal booking among HIV-positive women as late bookers were underrepresented in the work presented in this thesis.

The number of negative experiences of maternity services around the time of delivery reported by women in this study is of concern. It is difficult to establish whether these experiences were due to pressures within maternity services in general or discrimination as a result of women's HIV-status. Further quantitative and qualitative work (including participant observation) with non-HIV specialist maternity care staff is required to elucidate knowledge of and attitudes towards HIV in order to identify and address potential gaps in professional development.

Finally, the work I present in Chapter Six is the first in a UK setting to specifically explore Pentecostalism in the context of HIV, although it was brief by necessity. A more in-depth ethnographic study including comparisons with other diasporic churches would generate richer insights, especially into how HIV is constructed and addressed within the church. Given the difficulties I encountered in gaining access to members of the clergy, I would suggest particular methodological considerations be given to how to approach working in churches such as the TCPM.

11.3 Implications for practice and policy

My primary aim in conducting this research was to generate findings that could be used to inform the delivery of services and improvement of healthcare to this group of women. The findings from this study have implications for the collection of surveillance data, clinical practice and broader governmental policy in the UK. It is to this that I now turn at the end of my thesis.

One of the most vulnerable groups identified in the qualitative phase of this study were women who had insecure immigration status. There are currently no data in the NSHPC on women's immigration status, which could potentially be an important predictor of clinical and service-related outcomes. However, collecting data on immigration status is particularly sensitive in a wider climate of increasingly hostile immigration policy. Furthermore, additional questions on notification forms run the risk of reduced response rates. A first step would be to consult the units that respond to the NSHPC on whether questions about immigration status would be acceptable and feasible. The findings from my study also underline the importance of improving data collection on items that are currently poorly completed such as date of antenatal care booking, date of arrival in the UK, maternal viral load at delivery and breastfeeding. Improving the robustness of current NSHPC data collection is likely to have a greater impact on future research than the addition of new items. With regards to the matched

SOPHID/NSHPC dataset, I was limited in the conclusions I could draw by the lack of data on emigration. A recent audit on loss to follow-up in HIV-positive adults (Clay 2013) estimated that one in four patients not attending for care were known to have left the UK. This suggests that such information is key to interpreting data on loss to follow-up from care, and may need to be collected routinely as part of SOPHID. I would also like to underline the importance of continued close collaboration between surveillance programmes and their NHS respondents, as has been the case in the recent BHIVA audit, to improve our understanding of surveillance data. However, despite the limitations, the data from the matched SOPHID/NSHPC dataset have provided valuable insights and highlight the valuable contribution of matched large epidemiological datasets in formulating a more coherent picture of HIV in the UK.

Work presented in Chapter Seven revealed that late antenatal booking and unplanned pregnancy were common in the context of HIV, suggesting failings in the delivery of sexual and reproductive healthcare to women living with HIV. This emphasises the importance of addressing reproductive intentions and contraception regularly among those who are diagnosed (British HIV Association 2012) and informing women about the importance of prompt presentation to antenatal services in order to safeguard maternal and child health.

Approximately one in eight women do not return for HIV care in the year after pregnancy. It is important for healthcare professionals to reflect on how best to create conditions for women to be able to successfully engage with care. The results from the qualitative phase of this research revealed that women engage with care if they feel that services have resonance and meaning in their lives. Securing the health of their children was of overriding importance to all the women I interviewed during pregnancy. I suggest that healthcare professionals encourage women to view ongoing engagement in care *after* pregnancy as an important step in maintaining both their health *and* their ability to look after their children. It is also important to note how closely ART was coupled with returning for care after pregnancy in both the quantitative and qualitative analysis. This may be an important reason to consider continuing ART after pregnancy, regardless of maternal CD4 count.

Several women interviewed in this study gave accounts of negative experiences during pregnancy mainly with regards to poor care within maternity services and abstaining from breastfeeding. This is important as not only is ensuring positive experiences of care a key component of the NHS Outcomes Framework (Department of Health 2012b), but also because negative experiences may impact on future engagement with services. More work needs to be conducted within maternity services to ascertain levels of stigma towards HIV-positive women. In the meantime the onus should be on those working within HIV services to provide training and education to non-specialist colleagues in order to address gaps in knowledge and stigmatising attitudes.

With regards to infant feeding, healthcare professionals should continue to be aware of the difficulties encountered by women in adhering to current UK guidelines on formula feeding. They have a responsibility to create an environment where women feel able to express their concerns and intentions openly and should be prepared to support the minority of women who will choose to breastfeed. This is consistent with the current national guidelines on infant feeding and HIV in the UK, which although recommending formula feeding, acknowledges that some women will choose to breastfeed and will require support rather than an automatic referral to child protection teams (Taylor et al. 2012). Finally, an important barrier to not breastfeeding is the patchy availability of free formula milk and sterilising equipment for those on low incomes. This puts women in an intolerable position in terms of safeguarding the health of their babies. I urge HIV centres with no clear provision for free formula and milk for their most vulnerable patients to address this as a priority in accordance with current standards of care for people living with HIV as outlined by the British HIV Association (British HIV Association 2012).

Women from Western Africa and those who arrived in the UK after conception appear to be groups who have poorer engagement with HIV care due to a complex constellation of structural and cultural factors. Healthcare professionals should be aware that women from these groups may have particular vulnerability in terms of stigma, disclosure, poverty, housing and immigration issues. The importance of third sector agencies in this regard cannot be underestimated at this time of decreased public spending, especially peer-support programmes (such as the mentor mother scheme coordinated by Positive UK[343]) which have been shown to improve maternal and child outcomes internationally (McColl 2012).

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[343] Positive UK, a London based charity that works with people living with HIV, provides information and workshops on all aspects of pregnancy as well as providing one-to-one support to women from others who have had a child whilst living with HIV. See Positive UK's website for further information http://positivelyuk.org/women/.

The findings in this study also have implications for policy at a broader level. Cuts in NHS spending will continue to erode the provision of maternity care in the UK resulting in increasing levels of dissatisfaction. Lack of funding also threatens the position of specialist midwives who are increasingly being expected to take on other responsibilities, leaving them less time to provide the exemplary care that has been described in this thesis. Furthermore, with choice being enshrined as a core value within the reorganised NHS, we are left to wonder whether this brings with it a set of market-derived values that fail to engage flexibly and compassionately with the complexity of healthcare in chronic illness.

The ongoing economic crisis and ensuing austerity cuts have prompted a predictable surge in anti-immigrant rhetoric and legislation amongst the political classes in the UK. This will fuel anxiety and further marginalise an already vulnerable group of people. An important and welcome development during the course of my research has been the change in NHS charging rules, allowing all patients free ART regardless of immigration status. This has removed an important and corrosive barrier to long-term engagement with HIV services in the UK. With this in mind, the government's recent pledge to restrict migrants' access to benefits and healthcare is of deep concern. By stripping the most vulnerable in society of their rights, we render their lives “bare” (Agamben 1998) and constrain their capacity to look after their health.

11.4 Final thoughts

I began this thesis by recounting Pauline's engagement with HIV services during and after her pregnancy. My clinical experience of working with patients such as Pauline has undoubtedly been the main driving force in the development of this study. As a doctor who has worked closely with HIV-positive migrant African women for over ten years, and as the daughter of a migrant mother who received poor care within maternity services in the 1970s, I am not a dispassionate observer but an advocate who seeks to address health inequities. I embarked on this study wanting to know more about how African women in the UK engage with HIV care during and after pregnancy in order to improve clinical practice. It soon became apparent that the complex and multidimensional nature of this research question demanded a combination of methodological approaches. Conducting mixed methods research at doctoral level as researcher has been challenging, demanding an in-depth knowledge of a range of methodological approaches as well as an engagement with literature from a wide range of disciplines. Furthermore, throughout the duration of my research I have found myself “betwixt and between” roles (Turner 1967: 93), as both an epidemiologist/anthropologist and as a clinician/researcher. However my ambiguous position at disciplinary margins has been transformative, not only in the knowledge I have been able to generate but also in the skills I have acquired that can now be applied to other similarly complex questions within public health.

As I reach the end of this thesis, I would like to emphasise that the vast majority of pregnant African migrant women living with HIV in the UK engage well with HIV services and interventions during and after pregnancy, resulting in low rates of vertical transmission. They describe good relationships with their HIV antenatal teams and most return to HIV services after pregnancy. On the one hand this reflects well on the multi-disciplinary antenatal HIV teams and provides evidence of best practice that can be used to inform other parts of NHS HIV services. However, these good outcomes are mainly down to the efforts of HIV-positive women to engage well with interventions, sometimes at great personal cost, and are a testament to their resilience and love for their babies. I would like to end my thesis by paying tribute to them.