

**THE CHALLENGE OF HIV WITHIN AN HIV SPECIALIST  
ANTENATAL CLINIC IN LONDON:  
PROVIDING AND RECEIVING CARE WITHIN AN HIV DIASPORA**

**BY**

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## **Declaration by Candidate**

I hereby declare that this thesis is my own work and effort and that it has not been submitted anywhere for any award. Where other sources of information have been used, they have been acknowledged.

Signature:

Date:

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## **Abstract**

The ability to prevent vertical transmission of HIV (where HIV is transmitted from mother to (unborn) baby in utero, at birth or through breastfeeding) is generally considered to be the most successful achievement of HIV biomedicine and care. Indeed if appropriate care and biomedical technologies are available, transmission rates can be reduced to less than 1%. However, there has been very little qualitative research investigating the contingencies and requirements of specialist HIV antenatal care in resource rich settings.

Adopting theoretical insights from Science and Technology studies (STS) and anthropology within a broader sociological frame, this research explores the challenges of HIV and the successful prevention of vertical transmission in a specialist antenatal clinic which arguably has access to the most advanced care and biomedical technologies.

In doing so, the thesis investigates the way in which the identity of a particular illness — specifically HIV — is maintained in social, clinical and technical domains. Moreover, it explores the requirements of successful specialist HIV antenatal care from the perspective of both practitioner and patient, and it considers how the interests of patients, (unborn) babies and health professionals are reconciled, if at all, within the clinic.

The description of specialist HIV and antenatal care provided in this study draws on empirical research conducted in an HIV specialist antenatal clinic housed within an acute National Health Services hospital in London, UK. The research makes a practical contribution to knowledge about specialist HIV antenatal care through theoretically informed reflections on some of the requirements and contingencies of providing and participating in specialist antenatal HIV care in London. Moreover, the research offers an analysis of the clinic that interrogates the relations between social dynamics, (bio)medical practice and technological interventions. In this way, the research also contributes to the social scientific HIV field by explicating how social

understandings of HIV and pregnancy are intimately entangled with (bio)medical practice, technological intervention, and what I have called an “HIV diaspora”.

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## **List of Acronyms/Abbreviations**

Abbott - Abbott Real Time HIV-1 assay  
AIDS - Acquired Immunodeficiency Syndrome  
ART- Antiretroviral Therapy  
ARVs - Antiretroviral drugs  
BASHH - British Association for Sexual Health and HIV  
BHIVA - British HIV Association  
CDC - Centres for Disease Control and Prevention  
CHIVA - Children's HIV Association  
CL Hospital - Central London Hospital  
CRFs - Circulating Recombinant Forms  
C-sections/sections - Caesarean sections  
DNA - Deoxyribonucleic Acid  
DOSH - The Department of Sexual Health  
ECHR - European Convention on Human Rights  
GP - General Practitioner  
GU - Gynaeco-urinary  
HAART - Highly Active Antiretroviral Therapy  
HIV - Human Immunodeficiency Virus  
INSTE - an HIV test that gives an immediate result  
IPV - Intimate Partner Violence  
MDT - Multidisciplinary Team  
MSM - Men who have sex with men  
MTCT- Mother-to-child transmission  
NHS - National Health Services  
NHS REC - National Health Services Research Ethics Committee  
NL Hospital - North London Hospital  
NNRTI - Non-nucleoside Reverse Transcriptase Inhibitor  
NSHPC - National Study of HIV in Pregnancy and Childhood  
PCR - Polymerase Chain Reaction  
PEP - Post-exposure Prophylaxis  
PrEP - Pre-exposure Prophylaxis

R&D - Research and Development office

REC - Research Ethics Committee

RNA - Ribonucleic Acid - HIV's genetic material is composed of RNA

Roche - Roche COBAS AmpliPrep/COBAS TaqMan HIV-1 Qualitative test

STIs - Sexually Transmitted Infections

STS - Science and Technology Studies

TB - Tuberculosis

TDM - Therapeutic Drug Monitoring test

WHO - World Health Organization

## **Chapter One: Setting the Stage — Preventing Vertical Transmission of HIV in London**

[I]f we are to understand the challenge of HIV (the human immunodeficiency virus), we must understand our field of inquiry (Rosengarten, 2009, p. 4).

This thesis explores the challenges of HIV and how the prevention of vertical transmission<sup>1</sup> of HIV and care for HIV-positive pregnant women is achieved in one of the UK's most prominent specialist HIV antenatal clinics. The purpose of such an inquiry is to contribute to understandings of successful care from the perspective of those receiving and those providing it. In this research, I observed and participated in the events that took place in one of the UK's most prominent and busy HIV specialist antenatal clinics for nine-months (2008-2009). The clinic was the perfect location to examine the way in which care for HIV-positive pregnant women takes place and how vertical transmission of HIV is prevented. This chapter will help situate the inquiry and broader context in which the research unfolded by providing an overview of some of the challenges of HIV as they exist outside of the clinic. The overview provided in this chapter is not meant to be a comprehensive outline of the history of HIV/AIDS, the prevention of vertical transmission or of the literature pertaining to the pandemic. Rather, my intention here is to situate the case study, outline the requirements of preventing vertical transmission of HIV, provide cursory information about the scale of the problem of HIV, and introduce the clinic wherein this research took place.

The chapter is structured as follows: it begins by providing an outline of the global HIV situation as well as a discussion of the requirements of the prevention of vertical transmission of HIV. This has been included to make clear that there is a stark global divide between geographical locations where people have access to technologies that have managed to turn HIV into a

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<sup>1</sup> Vertical transmission of HIV is also known as mother-to-child transmission (MTCT).

chronic condition and areas where HIV is a precursor to death. The divide is central to the findings of the thesis and to my concluding argument. In the next sub-section, I give an epidemiological overview of the history of the prevention of vertical transmission of HIV in the UK. This is followed by an outline of the guidelines and actual care practices for the prevention of vertical transmission of HIV in the UK as well as statistical information about the HIV epidemic in the UK (with a focus on HIV-positive women — in particular, HIV-positive women in London). The chapter will then provide a preliminary ethnographic description of the clinic and an explanation from the perspective of the healthcare practitioners of the process women go through to become patients there. I conclude with a chapter breakdown of the literature review, methodology and empirical research.

#### **The global HIV pandemic: Preventing vertical transmission of HIV**

UNAIDS estimates that in 2012 there were 35.3 (32.2-38.8) million people living with HIV (UNAIDS, 2013, p. 4) and that approximately 25 million (23.5-26.6 million) of them live in sub-Saharan Africa (UNAIDS, 2013, p. 3). Moreover, in the same year (2012) only 9.7 million people living with HIV had access to antiretroviral therapy in low- and middle-income countries (UNAIDS 2013, p. 1).

Towards the end of the twentieth century, the use of a combination of antiretroviral drugs (here on referred to as ARVs) drastically altered the course of the HIV pandemic (Anderson and Doyal, 2004; Detels et al., 1998, p. 1497; Dieffenbach and Fauci, 2009; Kaplan et al., 2009; Palella et al., 1998, p. 853), changing the prognosis of an HIV-positive person from almost certain death to a life with a chronic illness (Carlsson-Lalloo et al., 2016; Siegel and Lekas, 2002, pp. S69-S70; Persson, 2013, p. 1067; van Sighem et al., 2010).

The prevention of vertical transmission of HIV-1<sup>2</sup> is generally considered to be one of the most successful achievements in the use of ARVs (Taylor, et al., 2012, p. 97). According to the Centers for Disease Control and Prevention (CDC), if a pregnant woman's HIV is diagnosed during or prior to her becoming pregnant and appropriate care and interventions are available and breastfeeding is avoided, the HIV transmission rate could be reduced to less than 1% (CDC, 2012, p. 1; Townsend et al., 2008, p. 937). The use of ARVs to prevent vertical transmission of HIV is synonymous with (using) treatment as prevention. Therefore, this entire thesis addresses treatment as prevention<sup>3</sup> as it pertains to the prevention of vertical transmission and the specific work that is carried out in the specialist HIV antenatal clinic. In what follows I will offer a brief description of efforts to prevent vertical transmission in the UK.

### **The history of the prevention of vertical transmission in the UK**

Tests that were able to detect antibodies to both HIV-1 and HIV-2 became available in the mid-1980s (Nicoll et al., 2000, p. 1). In the UK, antenatal HIV

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<sup>2</sup> An explanation of HIV-1 and HIV-2 will follow.

<sup>3</sup> Treatment as prevention is perhaps most commonly associated with efforts to prevent transmission of HIV between adults. In regards to this, a report was published in 2008 which had a monumental impact on the HIV biomedical and social science field (Persson, 2010). The report is usually referred to as the "Swiss Consensus Statement", and was published by the Swiss federal Commission for HIV/AIDS (Wilson et al., 2008). The statement claims that HIV-positive people who are receiving effective Antiretroviral Therapy (ART) — and consequently have an undetectable viral load — and are without STIs are sexually non-infectious (Wilson et al., 2008; Vernazza et al., 2008). Thus, the study claimed that treatment could prevent HIV infection between adults in serodiscordant sexual relationships. Hence, the Swiss statement directly pertained to HIV-positive adults who were in sexual relationships with HIV-negative people. In other words, the Swiss statement concerned the transmission of HIV through sexual contact between adults and not through vertical transmission.

The significance of the Swiss statements' is that it partially *proved* that treatment could be used as an effective HIV prevention method. Therefore, the statement can be seen to mark a different approach to HIV. This new approach uses treatment as prevention (TasP). The treatments that are perhaps most commonly associated with treatment as prevention are: pre-exposure prophylaxis (PrEP) which utilises a combination of different ARVs to protect HIV-negative adults from HIV; pre-exposure prophylaxis (PrEP) should be taken by the HIV-negative adults prior to exposure to HIV (McCormack et al., 2015). Moreover, it was deemed advisable to give post-exposure prophylaxis (PEP) (which is a combination of ARVs) to people after they had possibly been exposed to HIV (Henderson and Gerberding, 1989). Clearly, neither of these prevention methods would pertain to efforts to prevent vertical transmission of HIV.

testing was first offered to pregnant women in 1985 (Duffy et al., 1998, p. 270). Following this, surveys began in 1988 in selected regions of England in order to establish the prevalence of HIV-1 infection amongst people assumed to be heterosexual (Ades et al., 1991, p. 1562; Nicoll et al., 1998, p. 254; Nicoll et al., 2000, p. 1; Taylor et al., 2012, p. 97). Anonymous unlinked residual blood samples from babies born in the regions included in the survey were tested for antibodies to HIV-1 (Ades et al., 1991, p. 1562; Brown et al., 2004, p. 160; Nicoll et al., 1998, p. 254; Taylor et al., 2012, p. 97). Consequently, each HIV-positive baby detected by the survey also revealed two HIV-positive adults.

Between 1988-1996, an analysis of the data collected by the national surveys showed that black African women and women with a history of injecting drug use were at most risk of HIV-1 infections (Nicoll et al., 1998, p. 257). Similarly, De Cock and Low wrote that African women in the UK had a higher seroprevalence than other women in the UK (1997, p. 1747). Moreover, London was discovered to be the city with the highest number of women who were HIV-positive and pregnant (Nicoll et al., 1998, p. 257). Based on this, Nicoll and colleagues argued that it was justifiable to create policies that would improve the HIV services available to black African women (1998, p. 256).

Since 1992, it has been the policy in the UK to offer every pregnant woman a confidential and voluntary antenatal HIV test in areas where the maternal HIV prevalence is high; elsewhere women who are at increased risk of being or becoming HIV-positive are also offered the test (Mercey et al., 1996, p. 1129; Nicoll et al., 1998, p. 253). However, as Mercey and colleagues point out, selective antenatal HIV testing has failed to detect the vast majority of cases (1996, p. 1129).

Thus, in the late 1990s HIV healthcare providers and epidemiologists voiced significant concern about the state of antenatal HIV care and screening practices in the UK (Tookey et al., 1998; MacDonagh et al., 1996; De Cock and Johnson, 1998; Nicoll et al., 1998). Much of the debate was highly critical

of the low rates of HIV detection in the UK and supportive of a move towards “universal access” to HIV testing during pregnancy, which was generally thought to be a crucial step towards normalising HIV testing during pregnancy (De Cock and Johnson, 1998; Mercey, 1998; Tookey et al., 1998). Normalising HIV testing during pregnancy was considered by many researchers to be vital in order to make testing more acceptable to pregnant women and their care providers (De Cock and Johnson 1998, p. 290; Mercey, 1998, p. 241). According to these researchers, normalisation would happen by making the test available to all pregnant women during their initial booking visit and as part of the package of tests already offered to all pregnant women (De Cock and Johnson 1998, p. 290; Mercey, 1998, p. 241).

However, there was also much deliberation about whether or not selective or universal HIV antenatal testing would be more (cost) effective (Gibb et al., 1998, p. 261). Selective testing would target women from known risk groups, that is Black African women and women who were known to be or to have been injecting drug users (Tookey et al., 1998, p. 135). Conversely, universal testing would target all pregnant women within a defined region (1998, p. 135.). Some of the primary concerns voiced about selective testing were that care practitioners might be reluctant to choose only certain groups of women for HIV testing during pregnancy out of fear of being perceived as discriminating against and stigmatising them (Gibb et al., 1998, p. 261). Thus, Duffy and colleagues argued that despite the fact that antenatal HIV testing was first offered to pregnant women in the UK in the mid-1980s, midwives and obstetricians were still disinclined to discuss HIV testing with their patients (Duffy et al., 1998, p. 270; Mercey, 1998, p. 242). Hence, whether or not a pregnant woman was offered an HIV test depended on which hospital she attended and the particular care provider she met with (Conaty et al., 2005; Duffy et al., 1998; Gibb et al., 1998; Jones et al., 1998; Nicoll et al., 1998, p. 253; MacDonagh et al., 1996; Sadler et al., 2006; Tookey et al., 1998). Consequently, Mercey argued that the UK lagged behind other countries when it came to providing pregnant women access to HIV testing (1998, p. 242). Moreover, Mercey argued that this was particularly reprehensible because since 1990 the UK had been adept at assessing the amount of

babies who are at risk of infection but had not attempted to reduce the risk these babies were under (1998, p. 242.). Finally, universal testing was ultimately considered to be the most cost effective and also the most able to detect HIV infection in women who were not identified as belonging to the known risk groups (Ades et al., 1999a, p. 271).

Following this, in 1999 targets were set for the universal offer of an HIV test as part of antenatal care in England (Cliffe et al., 2001, p. 376; Townsend et al., 2006, p. 248). The targets were intended to obtain the national goal of reducing the amount of babies who acquired HIV through vertical transmission by 80% by the year 2002 (Adam, 1999, p. 2). An initial step in achieving these goals was a directive where all health authorities in England were asked to ensure that “all pregnant women [were] offered and recommended an HIV test as an integral part of their antenatal care” (Adam, 1999, p. 2). A caveat was included for women who booked in while in labour or who were otherwise too late to receive antenatal care; these women would be offered a test postnatally (1999, p. 2).

The new screening targets were thus implemented in the same year that Ades et al. observed that out of the over 300 HIV-positive women who gave birth in the UK every year, more than 75% of the women had not had their HIV infections diagnosed at the time they gave birth (1999b, p. 1230). Furthermore, Postma et al. commented on the fact that despite existing guidelines on antenatal screening, few women in the UK actually screened for HIV during pregnancy compared to countries with similar access to care and health technologies (1999, p. 1656). Importantly, however, when HIV was detected antenatally the medical and care interventions available in the UK were very successful and led to the reduction of vertical transmission of HIV and the decline of HIV related morbidity (Duong et al., 1999).

By 2002, one-third of the English units that provided antenatal care reported a 90%+ uptake of HIV antenatal testing (Townsend et al., 2006, p. 248). Since then, the rates of vertical transmission in the UK have been on a continuous decline since 2006 “reaching an all-time low of 5 per 1000 in 2010-2011”

(Townsend et al., 2014, p. 1049). Moreover, the number of HIV-positive mothers in the UK who go on to have additional pregnancies is on the rise (French et al., 2012, p. 287). The effectiveness of the British guidelines for the care of HIV-positive pregnant women in preventing vertical transmission were confirmed by Townsend et al. (2008).

In 2004, the Health Protection Agency noted that while HIV screening should be available to all pregnant women, those who were refugees and asylum seekers — and had recently arrived to the UK from high prevalence countries (as well as injection drug users and sex workers) — were at particularly high risk (The UK Collaborative Group for HIV and STI Surveillance, 2007, p. 47).<sup>4</sup> Furthermore, the Health Protection Agency found that in 2006 pregnant women from [born in] Sub-Saharan Africa had the highest HIV prevalence in the UK (2007, p. 90). Moreover, in the same year, the second highest HIV prevalence was amongst pregnant women who had been born in the Caribbean and Central America (2007, p. 90). Further to this, Tariq and colleagues found that in the UK, pregnant HIV-positive Black women of African ancestry or otherwise are more likely than white HIV-positive women to be late in booking their first antenatal appointment (2012a, p. 978). Problematically, evidence shows that late booking increases the risk of vertical transmission and adverse health outcomes for both mother and baby (2012a, p. 978). Therefore, while universal testing and antenatal HIV care have undoubtedly been overwhelmingly successful in the UK in preventing vertical transmission, certain groups of women are still more at risk.

This disparity is especially apparent in London compared to the rest of the UK. Public Health England estimated that in 2011 the HIV prevalence amongst pregnant women in London was 3.5 per 1,000, whereas the prevalence in the rest of England was 2.2 per 1,000 (Aghaizu, 2013, p. 8). Overall, the prevalence was the highest amongst women originally from Sub-Saharan Africa with 23 per 1,000 being HIV-positive (2013, p. 8; Taylor, 2012, p. 97). In comparison, UK-born pregnant women had a prevalence of 0.5 per

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<sup>4</sup> Please note that the reference was authored by the UK Collaborative Group for HIV and STI Surveillance, but published by the Health Protection Agency.

1,000 (Aghaizu, 2013, p. 8). Further to this, the British HIV Association (here on referred to as BHIVA) reports that since 2000 approximately 10 cases of vertical transmission of HIV from women diagnosed with HIV prior to delivery are reported every year in the UK (Taylor, 2012, p. 97). Furthermore, every year approximately 20-30 children who were born in the UK to mothers who were not known to be HIV-positive at the time of the child's birth are diagnosed with HIV (2012, p. 97).

### **Encountering the HIV specialist antenatal clinic and preventing vertical transmission of HIV**

This research uses qualitative methods to explore an HIV antenatal specialist clinic. As mentioned above, I spent nine months in the clinic gathering data. In particular, I was interested in what makes everyday life and HIV positivity compatible, and the prevention of vertical transmission of HIV possible in the clinic. Moreover, I was interested in how the prevention of vertical transmission of HIV and care for HIV-positive pregnant women is *done* in clinics that had access to the most advanced biomedical resources, information and skilled medical practitioners. In what follows, I set out the empirical scene in which my study took place.

The Department of Sexual Health (DOSHS) at "London Hospital" in an inner city area of London is home to one of England's busiest HIV centres. The centre facilitates several satellite clinics, one of which is the HIV specialist antenatal clinic. It is a once-weekly open clinic for pregnant HIV-positive women in the local community and is held in the hospital's antenatal department. Approximately 40-50 HIV-positive pregnant women receive care in the clinic every year. Other antenatal specialist clinics, such as a clinic for women with diabetes, may simultaneously convene in this space.

DOSHS has a multidisciplinary approach to HIV care. A group of health care professionals, some of whom specialise in HIV and some who are based at other hospitals in London (an HIV specialist paediatric nurse, and an HIV

specialist community nurse), will care for the clinic's patients and/or their families.<sup>5</sup> They are called the Multidisciplinary Team (here on referred to as MDT); a more detailed description of the team will be provided in Chapter Three. The core members of the team responsible for antenatal patients usually attended clinic meetings on a weekly basis: Ellen,<sup>6</sup> an HIV specialist midwife, Sophia, an HIV specialist doctor, and an HIV consultant physician, known as either Anne or Marie.<sup>7</sup> The patients would most often see both Sophia and Ellen on days that they visited the clinic; the specialist consultant physicians rarely stayed for patient consultations. Patients are regularly sent to other areas of the hospital to carry out different procedures such as filling out prescriptions, having blood taken, and sexually transmitted infection (STI) screenings. Ellen, the specialist midwife, was the only MDT member who exclusively cared for the HIV specialist antenatal clinic's patients. Other members of the MDT periodically attend meetings depending on specific issues relating to a patient, such as foetal abnormalities, the presence of other children who might need testing, and obstetric interventions such as scheduled cesarean sections.

The clinic convenes in the antenatal department in a purpose-built modern hospital building. It is accessed via the main entrance hall of the hospital beyond a waiting area, reception, café and convenience store. There, a large sign above the entrance to a corridor informs you that if you follow the coloured lines on the laminated floors of the hospital, you will be directed to the various wards beyond the main building. Upon entering the reception area of the clinic, the patient is required to register with the receptionist, receive her antenatal file which contains medical notes as they pertain to her antenatal care, and then sit down in the waiting room. The waiting room is light and airy with several rows of chairs. Two televisions are mounted on the walls. They play a reel of advertisements and public health alerts on a loop, extolling

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<sup>5</sup> In fact, most of the members of the MDT were not actively involved in the patient's care until she had had her final postnatal appointment at the specialist antenatal clinic and had her care transferred to other clinics.

<sup>6</sup> As will be discussed in Chapter Three, all of the research participants within this thesis have been given pseudonyms.

<sup>7</sup> Marie filled in for Anne during the autumn. Anne took charge of the clinic after the Christmas hiatus.

advice on issues such as how to care for one's self and their babies, the best car seats to buy and breastfeeding techniques to employ. There is an occasional advertisement aimed at male viewers, assuring them of their usefulness and the importance of involvement in their partner's pregnancy and their baby's life. Posters are also plastered on the walls, giving advice and warnings: what and when to eat, not to smoke or drink, and so on.

There is a general sense of urgency on the part of the employees of the clinic, expressed in their tone of voice, purposeful walk and the way they deftly guide patients through the various rooms and stages. The professionals' efficiency is in stark contrast to the slow and awkward movements made by the pregnant women, as they slouch in their chairs, looking as if they have resigned themselves to an undetermined wait. Various healthcare providers from other clinics come in and out of the waiting room calling patients' names, often mispronouncing them. They wait while the patients gather their belongings and follow them into the consultation rooms. Patients are occasionally greeted with a warm smile or a hug. At other times the employees tap their feet as they impatiently wait for the women to waddle over to them.

### **Becoming a patient**

In the following section, I will use the practitioners' description of the process to explain how women become patients in the clinic. It is worth mentioning that the description reflects on how the practitioners told me they *plan* a patient's introduction to the clinic. In practice, as we see later, care is much more complicated than I am able to make allowances for here. These complications will be considered in the empirical chapters of this thesis.

Practitioners working in the clinic are alerted to a patient's existence via external sources such as DOSH, the virology department in another hospital

in London,<sup>8</sup> GP offices, community midwives, and routine gynaeco-urinary (GU) screens. These sources provide the clinic with the initial test results, both for pregnancy and of HIV-positivity. However, a woman will only become a patient in the clinic if she intends to keep her pregnancy. In this way, some women might be known to be HIV-positive and pregnant, but they might never be cared for in the clinic because they choose to terminate their pregnancies.<sup>9</sup> If a patient is unaware of her HIV status, the HIV specialist midwife will recall the patient to communicate these results and accompany the patient to the DOSH for registration,<sup>10</sup> and for baseline HIV blood tests, including a CD4 count<sup>11</sup> (indicates how well the immune system is working) and viral load tests<sup>12</sup> (amount of virus in a blood sample) (AIDS.gov, 2015; Carter and Hughson, 2014; San Francisco AIDS Foundation, 1998). The two tests are the primary way in which disease progression is monitored. The results from the tests will also be used to decide upon an appropriate treatment regime: the patient's medical and social background will also be assessed, as these might complicate the administration of certain treatments.

To monitor and quantify the viral load there were several different commercial assays available within the National Health Services in the UK at the time of this study. The assays most commonly used to assess the London clinic's samples are the Roche COBAS AmpliPrep/COBAS TaqMan HIV-1 Qualitative test and the Abbott RealTime HIV-1 (ROCHE and ABBOTT for short)(de Ruiter et al., 2008, p, 465; Sloma, 2009).

ROCHE and ABBOTT are sensitive to various strains of HIV. Essentially there are two types — HIV-1 and HIV-2 — and both have the same mode of transmission. However, HIV-2 tends to be harder to transmit than HIV-1 and it

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<sup>8</sup> London Hospital does not have its own virology department. Therefore, as per contract between the two NHS trusts, in the first instance London Hospital sends their blood samples to a hospital in another health trust.

<sup>9</sup> A woman might also miscarry before she has become a patient.

<sup>10</sup> The HIV specialist midwife arranges these appointments outside of the weekly HIV specialist antenatal clinics.

<sup>11</sup> CD4 cells are white blood cells and are an essential part of the immune system. HIV usually infects CD4 cells which eventually leads to more copies of the virus being made. There is usually a decrease in the CD4 cell count when a person has HIV.

<sup>12</sup> Indicates the severity of a viral infection which is estimated by measuring the amount of "virus" (HIV RNA particles) in a blood sample.

is also thought to be relatively uncommon, especially outside West Africa (Heimer, 2007, p. 552). Moreover, there are several different strains of HIV-1. The most common of these is called group “M” and approximately 90% of HIV-1 infections are thought to belong to this group. Within this group there are at least nine genetically distinct subtypes, referred to as A, B, C, D, F, G, H, J and K. Furthermore, it is possible, although rare, for two different sub-strains of the virus to meet in the cell of an infected person and mix their genetic material, consequently producing a new “hybrid” virus. The hybrid strains that “survive” and infect more than one person are referred to as circulating recombinant forms (CRFs). The various subtypes of HIV-1 have been allocated specific geographical locations where they are understood to be most prevalent (AVERT, 2014; Cohen et al., 2008, p. 1244). The excerpt below describes the global spread of these subtypes.

- The HIV-1 subtypes and CRFs [circulating recombinant forms] are typically associated with certain geographical regions [...] As studies have shown, individuals are increasingly presenting with sub-types not native to the country of diagnosis....
- Subtype A and CRF A/G predominate in West and Central Africa, with subtype A possibly also causing much of the Russian epidemic.
- Historically, subtype B has been the most common subtype/CRF in Europe, the Americas, Japan and Australia and is the predominant subtype found among MSM [men who have sex with men] infected in Europe. Although this remains the case, other subtypes are becoming more frequent and now account for at least 25 percent of new HIV infections in Europe.
- Subtype C is predominant in Southern and East Africa, India and Nepal. It has caused the world’s worst HIV epidemics and is responsible for around half of all infections.

- Subtype D is generally limited to East and Central Africa. CRF A/E is prevalent in South-East Asia, but originated in Central Africa. Subtype F has been found in Central Africa, South America and Eastern Europe. Subtype G and CRF A/G have been observed in West and East Africa and Central Europe.
- Subtype H has only been found in Central Africa; J only in Central America; and K only in the Democratic Republic of Congo and Cameroon (AVERT, 2014).

The significance of the above is that at the time of this study, some of the older commercial assays were still in use within the NHS and might falsely indicate that an individual with “divergent subtypes” has a low or undetectable viral load (de Ruiter et al., 2008, p. 465). BHIVA recommends re-testing with another assay if there are discrepancies in a patient’s clinical status, viral load and CD4 count (2008, p. 465). However, not all discrepancies are necessarily assay or subtype related; according to the BHIVA, “[a]lthough rare, some untreated individuals may have an undetectable viral load in conjunction with low CD4 cell counts” (de Ruiter et al., 2008, p. 465). Accordingly, the ROCHE assay occasionally under-quantifies the viral loads of the clinic’s patients, making the patient seem *healthier* than she actually is. ABBOTT is therefore the MDT’s ideal assay, as it is *more sensitive* and is consequently in higher demand.

Moreover, the manner through which a woman’s HIV is managed during pregnancy varies depending on a number of factors such as whether or not she conceived while taking Highly Active Antiretroviral Therapy (here on referred to as HAART), or if she started taking it during pregnancy, if she has other infections or illnesses such as Tuberculosis (here on referred to as TB) or Sexually Transmitted Infections (STIs), if she is or becomes resistant to any of the drugs commonly used, if her viral load fails to be suppressed, and so on and so forth (Taylor, et al., 2012, p 101). The practitioners will decide upon an appropriate regime based on the patient’s particular medical history as well as her lifestyle and wishes. In accordance with official guidelines, for their own

health the MDT would like all of their patients to start taking ARVs at twenty-four week's gestation if they have not already begun to do so, as in the case of women who knew their status prior to conception, and women who commenced treatment earlier in pregnancy (2012, p. 108).<sup>13</sup>

The possibility of a (unborn) baby becoming infected with HIV through vertical transmission is related to a pregnant woman's viral load; essentially, the higher it is, the greater the risk. Hence, the patient's viral load and CD4 count is monitored throughout her pregnancy to ensure the effectiveness of her treatment regime. A successful regime would ensure that her viral load is undetectable by the time she is ready to give birth.<sup>14</sup> The regime involves administering a Therapeutic Drug Monitoring test (TDM) two weeks after the patient starts taking ARVs. The test evidences the amount of drug (ARVs) in the patient's blood. If the test results show that the patient does not have the expected amount of drug in her body, this alerts the team to the fact that something is wrong. The patient may not be taking the prescribed doses in the right way at the right times, or the drugs may not be working *properly* in her body on the virus.

The frequency of the patient's appointments in the clinic depends on the gestation of her pregnancy and her mental and physical health. If necessary, the MDT will offer further support according to the women's individual needs throughout the entire pregnancy, as well as her birth experience and any issues that arise postnatally. At around twenty-four to thirty weeks' gestation, the HIV specialist midwife, as part of the MDT, decides upon a birth plan in consultation with the patient. A copy of the birth plan is given to the patient to put in her antenatal notes and a copy is given to the labour ward. The birth plan is a crucial *stand-in* for the MDT, if they are absent at the birth. The plan provides detailed instructions on how to manage the patient's HIV during and after labour along with initial care for the baby.

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<sup>13</sup> If no interventions are made, the risk of vertical transmission of HIV is estimated to be between 25% to 40% (Newell, 1998).

<sup>14</sup> The meaning of an undetectable viral load will be considered further in Chapter Four.

Women with an undetectable viral load are usually encouraged to have a vaginal birth. If the mother has a vaginal delivery, she will present herself at the labour ward at the onset of her labour. She will inform staff that she is a patient of the HIV specialist midwife. This will alert them to her serological (HIV) status. They will then consult her birth plan and follow the guidelines that the specialist midwife has set out. If it has been decided that the patient will have a caesarean section, she will be admitted to hospital the day before the scheduled surgery. The HIV specialist midwife will admit her and make sure that any necessary medication is administered and that she is fully aware of what will happen over the whole delivery process. The next day, the surgery is performed and the patient is presented with her baby. Ideally, the HIV specialist midwife should be present throughout and an MDT obstetrician should perform the surgery. In the case of both vaginal deliveries and caesarean sections, staff will ensure that all confidentiality agreements laid out in the birth plan are met in order to avoid disclosure of the patients' HIV status to unwitting witnesses at the birth, such as partners that have yet to be informed of the patient's HIV-positivity. After the birth, the mother will recover from the procedure in the maternity ward. The length of her stay in hospital will depend on her relative health and speed of recovery. A healthcare professional will make a few home visits during the first few weeks of the baby's life, and at six weeks the new mother will come in for her last appointment with the HIV specialist antenatal team. After this, the mother will receive all of her HIV care at the DOSH and her baby will be cared for in the paediatric ward at the London Hospital.

The neonatal management of infants born to HIV-positive women varies depending on the status of the mother, e.g. when the mother started taking HAART, and her viral load (Taylor, et al., 2012, p. 128). Infants born to HIV-positive mothers are tested with either HIV Deoxyribonucleic acid (DNA) the polymerase chain reaction (PCR) or HIV RNA tests at the following times: at some point during their first forty-eight hours before being discharged from hospital, at six weeks of age, and at twelve weeks. Additional testing is advised for infants who are at increased risk of transmission, for example, if

the mother has been known to breastfeed (2012, p. 132).<sup>15</sup> In situations where transmission risk is considered to be low, because of the mother's suppressed viral load, the preferred treatment for the infant would be Zidovudine monotherapy (one drug), administered twice a day for four weeks (2012, p. 128). If the infant is not (and has never been) breastfed, and all of the tests have been negative at twelve weeks, BHIVA advises that the parents are told that the baby is HIV-negative (2012, p. 132). Still, at eighteen months the toddler will be tested for the last time to ensure that it has not seroconverted, meaning that it has not become HIV-positive (Taylor, et al., 2012, p. 132).

The description of the HIV specialist clinic above is derived from the observations I made while in the clinic — stories the practitioners told me and the clinical guidelines that informed the care provided to the patients. It is an account that focuses on the various technical diagnostic tools used by the MDT for the benefit of the clinic and its patients. Therefore, it is an account of the clinic that mostly avoids recounting the messiness that care in practice always entails. As mentioned previously, these stories will be saved for later chapters. Here I would like to make clear that the clinic is able to provide the most advanced care, biomedical technologies and medicines for HIV-positive pregnant women. In this clinic the prevention of vertical transmission is the norm. Analysing a clinic in such a prominent position allows for an investigation into a clinical environment wherein the care provided is not restricted because of lack of resources. In other words, whatever the challenge(s) of HIV may have been in the clinic, lack of resources did not feature as a primary concern. Thus, by choosing a location wherein resources were (comparatively) abundant, I was able to explore the challenge(s) of HIV in an environment that was best-equipped to negotiate and contend with them.

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<sup>15</sup> In accordance with national guidelines since 2001, HIV-positive women in the UK have been advised to entirely avoid breastfeeding (Hawkins et al., 2005; Lyall et al., 2001; Taylor et al., 2012).

## Structure of the thesis

In Chapter Two, I will discuss a diverse set of literatures to create a theoretical framework able to explore the processes and socio-political complexities involved in HIV and prevention of vertical transmission of HIV in the London clinic. The chapter begins by reviewing qualitative studies that consider the problem of HIV in the UK, specifically as it pertains to vertical transmission and pregnant HIV-positive women originally from Sub-Saharan Africa. This initial section of the chapter will also reflect upon social scientific literatures that consider the HIV/AIDS epidemic in order to explore significant themes evident in the UK based studies. I will then outline the work of Didier Fassin and show how his contribution enables consideration of the effects that geopolitical concerns and scientific developments may have on the resources available to people living with HIV and the experience of being HIV-positive and pregnant. Moreover, arguments made by both Marsha Rosengarten and Nancy Scheper-Hughes will be considered in this chapter and re-threaded throughout the rest of the thesis. Following this, I will discuss how the work of Science and Technology Studies (STS) scholars, Annemarie Mol in particular, may assist in making sense of the challenges associated with providing care to HIV-positive pregnant women and attempting to prevent vertical transmission. I will demonstrate throughout how the various literatures assist my arguments in each subsequent chapter.

Influenced by the methodological approach used by Annemarie Mol (and in collaboration with John Law), Chapter Three will show how my extension of their contributions and the methods chosen for this project assists in the exploration of the requirements of *good* HIV specialist antenatal care. Further to this, the chapter will provide a description of the methods and my methodological approach to conduct this study. Moreover, consideration will be paid to the emotive concerns that arose for me during the research process.

Chapter Four will examine the limitations and particularities of some of the

biomedical technologies that the practitioners in the clinic use to inform their practice. I will argue that the technologies in question have the potential to mirror issues related to the global HIV pandemic. This discussion will help clarify the complex and varied work that the practitioners engage in to provide their patients with care. Additionally, the chapter will argue that the practitioners' care efforts are directed at the patient and her offspring in accordance with how the practitioner imagines them to have the potential to become in the future. Consequently, the chapter will begin to detail the components and requirements of the provision of good care in the clinic and describe the patients, postnatal women and babies, who are the (potential) beneficiaries of care.

This exploration will continue throughout Chapters Five and Six from different vantage points. Each of these perspectives will assist in clarifying what care in the clinic constitutes and what is at stake for practitioners and patients in its provision. Recurring themes in each chapter will be the significance and implication(s) of a patient's immigration status and country of origin. The final chapter will reflect upon the arguments made in this thesis and consider how they might benefit efforts to care for HIV-positive pregnant women.

## **Chapter Two: Framing the Challenge of HIV in the Specialist Antenatal Clinic**

As mentioned in the previous chapter, the stated aim of this thesis is to investigate the challenges of HIV and successful care in an HIV specialist antenatal clinic. My intention is to make a practical contribution to knowledge about specialist HIV antenatal care in London by offering theoretically informed reflections on some of the contingencies of providing and receiving care. To begin this investigation, this chapter poses the question: what is the problem of HIV (during the antenatal period) in places wherein access to biomedical technologies and specialist care is not (comparatively) restricted?

In order to explore this question, this thesis will investigate what HIV *is* in the specialist clinic, both as it is “[achieved] as a seemingly stable object”, and as it is experienced by the patients and practitioners (Rosengarten, 2009, p. 28). Hence, it is necessary for me to set up a framework that is able to contend with a multitude of things, or what Mike Michael and Marsha Rosengarten have called “an intricate assemblage of multiple phenomena” (2013, p. 37), without privileging any of the various components involved. Accordingly, in what follows I provide a review of literatures that pertain to Black (African) HIV-positive pregnant women in the UK and the provision of antenatal care to them. Key themes and areas of concern evident in these studies will then be explored in relation to literatures that have diverse theoretical approaches.

The chapter is structured as follows: it begins by examining the scarce qualitative studies that consider HIV and pregnancy amongst Black and Black African women in the UK. My intention is to discover how these studies conceive of the problems of HIV in UK antenatal clinics. Aided by social scientific studies that concern the HIV/AIDS pandemic, I will discuss several issues that emerged within these UK based studies. After this, the chapter will introduce three different sets of theoretical literatures that address the areas of concern outlined in the UK based studies. Moreover, I will make clear

throughout the chapter how these various theories and literatures will be used in subsequent chapters.

Below is a brief description of the three different areas of concern and a cursory description of the literature that will be used to explore them:

1) The UK based studies find that *something* about the patient's diasporic positionality makes it difficult for them to fully engage with the interventions and care on offer in the UK. To explore this, I will consider anthropological literatures that help to further investigate the significance of the patients' location within a diaspora. This section will provide a way of considering the consequences of a patients' movement between different geographical spaces.

2) Moreover, the UK based studies draw attention to the fact that patients' experience and understanding of HIV biomedical interventions and technologies may be drastically different from their medical practitioners, which could lead to problems in the clinic. In order to investigate this theme, I will discuss literature that explores the way in which a specific disease can be *done differently*.

3) Finally, the studies highlight the significance of the care that patients receive and the relationships established between practitioner and patient. Thus, the chapter will end by discussing literature that considers the importance of the care on offer in the clinic.

### **Qualitative studies pertaining to HIV specialist antenatal care and Black African women in the UK**

As discussed in the previous chapter, Black African women (and women of other black backgrounds) are disproportionately affected by HIV in the UK, particularly in London (Nicoll, et al., 1998; Gibb et al., 1998). Therefore, I will explore qualitative studies that concern their particular circumstances.

However, there are very few UK based qualitative studies that consider issues related to HIV-positivity, pregnancy and/or motherhood (Tariq, 2013, pp. 48-49). Additionally, even fewer specifically concern the experiences of Black and/or African pregnant women living with HIV in the UK.<sup>16</sup>

In 2012, Shema Tariq and colleagues cited two UK based qualitative studies that considered HIV and pregnancy and included women originally from Africa,<sup>17</sup> both of which were unpublished and had small sample sizes (2012b, p. 2).<sup>18</sup> Moreover, in 2013 Tariq identified only seven UK based qualitative studies that considered HIV-positivity and pregnancy and/or maternity (2013, p. 49).<sup>19</sup> Furthermore, only five of these studies cited by Tariq explored antenatal care and HIV-positivity (2013, pp. 49-50).<sup>20</sup>

In addition to the articles cited by Tariq, she has, to the best of my knowledge, been involved in most of the significant published articles<sup>21</sup> which used a qualitative methodology and concerned Black (African) HIV-positive pregnant women living in the UK (Dhairyawar et al., 2012; Tariq et al., 2012b; Tariq et al., 2014; Tariq et al., 2016).<sup>22</sup> Because these studies all use the data and findings from Tariq's unpublished PhD thesis,<sup>23</sup> the primary focus in the

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<sup>16</sup> There have, however, been more notable qualitative studies that consider pregnancy and other aspects of being a woman living with HIV in resource rich settings such as: Keegan et al., 2005; Jarman et al., 2005; Psaros et al., 2012; Richter et al., 2002; Sanders, 2008, 2009; Siegel et al., 2006; Giles et al., 2009; Gurevich et al., 2007; Kelly et al., 2012).

<sup>17</sup> Additional studies consider the experiences of HIV-positive pregnant women in the UK, although the participants were all white and from the UK/Europe (Kelly et al., 2012; Wilson, 2007).

<sup>18</sup> One of these studies is an unpublished MA Thesis (Carter, 2009) and the other was presented at a conference (Naftalin et al., 2010).

<sup>19</sup> In her thesis, Tariq cites six articles, but she lists seven in total. I believe the discrepancy is because Kelly et al. wrote two articles, which Tariq cites, but she has only "counted" one of them (Tariq, 2013, pp. 49-50). In addition to the articles listed in the footnote below Tariq cites the following articles here: Doyal and Anderson, 2005; Wilson, 2007.

<sup>20</sup> Tariq cites the following articles: Carter, 2009; Kelly et al., 2012, 2013; Naftalin et al., 2010; Treisman et al., 2014. Please note that Tariq cites the article by Treisman et al., as having been published in 2013 (Tariq, 2013, p. 50).

<sup>21</sup> However, there are other qualitative articles that have been published — some of these will be discussed in this chapter.

<sup>22</sup> This was the first qualitative paper to investigate the experiences that women living with HIV had with infant feeding in a "high-income setting" (Tariq, 2016, p. 5). The paper examines the way in which African women living with HIV in the UK make decisions about infant feeding (2016).

<sup>23</sup> Moreover, quantitative data from this same study was used to analyse the effects of two different "combinations of ARVs commonly used in 'resource rich settings'" (Tariq et al., 2011a); for a study that used epidemiological data pertaining to the use of ART and HIV-

following will be to provide more information about her thesis. After this, I will explore prevalent themes apparent in the studies mentioned above.

As an HIV specialist physician who worked as an HIV doctor at Homerton University Hospital<sup>24</sup> prior to and during the research period (Tariq, 2013, p. 85), Shema Tariq explored in her PhD thesis how African pregnant and postnatal women living with HIV in the UK engage with HIV services and interventions during the antenatal period and postnatally (2013, p. 14). Tariq used a mixed methodology to explore her primary research question (2013, p. 14)<sup>25</sup> which was “how do African women living with HIV in the UK engage with HIV services and intervention during and after pregnancy (Tariq, 2013, p. 14)?” The study was comprised of epidemiological data amassed during 2000 and 2010 by the UK’s and Ireland’s National Study of HIV in Pregnancy and Childhood (NSHPC),<sup>26</sup> pertaining to about 12,000 pregnancies. This involved interviews with pregnant African women living with HIV receiving care in HIV specialist antenatal clinics in London, healthcare professionals, voluntary sector workers and members of a Pentecostal church. Moreover, ethnographic data was collected in an HIV charity, a Pentecostal church and three HIV specialist antenatal clinics in London (Tariq et al., 2012b, p. 1; Tariq, 2013, pp. 14, 83-84, 86-90).<sup>27</sup>

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positive women’s maternal viral load at the delivery of their second babies (French et al., 2014); and for a study that investigated the association between “detectable maternal viral load at delivery and MTCT in pregnancies in women with HIV born in Sub-Saharan Africa” (Tariq et al., 2011b). Moreover, epidemiological data from the same study was used to investigate the association between the ethnicity of HIV-positive pregnant women and late antenatal booking (Tariq, et al., 2012a).

<sup>24</sup> Tariq does not provide Homerton University Hospital with a pseudonym in her thesis. Please see: Parisaei et al., (2007) for an article that compares the deliveries of HIV-positive women and women from the general population that give birth at Homerton University Hospital.

<sup>25</sup> For a discussion on the benefits of using this methodological approach when exploring HIV and pregnancy amongst African women living with HIV in the UK please see: Tariq and Woodman, (2010).

<sup>26</sup> The NSHPC is a surveillance program that has been collecting data in the UK and Ireland since 1986, on pregnant women and women who give birth and have been diagnosed with HIV (Tariq, 2013, p. 60). For more information about the NSHPC, please see: <http://www.ucl.ac.uk/silva/nshpc>.

<sup>27</sup> Many of the clinical consultations that Tariq observed were her “own” (2013).

Tariq's findings were overwhelmingly optimistic (2013, p. 300). Indeed she concluded that practically all HIV-positive pregnant women in the UK take ART during pregnancy and "achieve virological suppression" by the time they are ready to give birth (2013, p. 294). Moreover, vertical transmission of HIV was incredibly unusual in the UK and most women engaged with HIV services after having been pregnant (2013, p. 294.). However, Tariq sites the following issues as being of concern: patients' experiences with "poor care" within other areas of the NHS, patients' negative experiences with interventions, and patients finding it difficult to refrain from breastfeeding (2013, pp. 294-295). Moreover, she found that Black (African) women living with HIV generally booked in for antenatal care later than white HIV-positive women (Tariq et al., 2012a, p. 978; Tariq, 2013, p. 294). In what follows, I will describe four of the themes that emerged in the studies cited above.

#### **Something about the patient's location within a diaspora disrupting care**

The studies mentioned above find that there is something about the patient's life and/or cultural, political, and social positionality outside of the clinic which may disrupt care (Tariq et al., 2012a, p. 978; Dhairyawan et al., 2013, p. 2; Tariq, 2013, pp. 201, 267-268; Tariq et al., 2014, p. 59). In other words, when care fails (according to these studies), the fault lies with *the social* and not *the biomedical*. Subsequently, Tariq contributes the success of care as being the result of the patients' engagement with care and (bio) medical technologies (2013, p. 300). Moreover, she argues that the complicated issues patients experienced (and which subsequently led them to reject care) were closely linked to their position within an "African diaspora" (Tariq, 2013, p. 300). She uses the concept to refer to "the contemporary global migrations of various African communities who retain relationships with their homelands and an ethnonational identification whether it is Yoruba, Nigerian or African" (2013, p. 34). Moreover, she argues that African diasporic HIV-positive women 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 (Tariq, 2013, p. 285).

In this way, Tariq ultimately found that “a complex constellation of cultural and structural factors including stigma and lack of UK citizenship rights emerged” as the most significant hindrance for women thus positioned to engage with care (2013, p. 14).

The UK based qualitative studies make a similar argument regarding a school of HIV social scientific research that labels various inequalities and social norms as being the key drivers that make an individual vulnerable to HIV, and are thus the driving force of the HIV pandemic (i.e. structural drivers) (Auerbach et al., 2011).<sup>28</sup> What’s concerning is that approaches which promote the significance of structural drivers have a tendency to view the social as being separate from (bio)medical practice “where sociality becomes the sphere of power dynamics that fuel the epidemic” (van der Zaag and McKnight, 2016: forthcoming). Instead the literatures that are critical of this approach do not position the social as being separate from the biomedical, rather they engage with the effects of the biomedical and biomedical interventions (Persson, 2013; Race, 2001; Rosengarten, 2009; van der Zaag and McKnight, 2016: forthcoming). Some of the arguments made in these literatures will be considered later in this chapter.

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<sup>28</sup> It is important to point out, however, that the UK based studies position structural factors as being the reason why HIV-positive black African women have difficulty engaging in care — rather than using the concept of structural drivers to consider a group’s vulnerability to HIV.

### **Problems with prevention technologies**

The studies above argued that prevention technologies such as replacement feeding<sup>29</sup> had multiple meanings and consequences for the women who engaged with them. Indeed, Treisman and colleagues report that the twelve African HIV-positive women they interviewed claimed that not being able to breastfeed was the most upsetting aspect of being an HIV-positive mother (2014, p. 145). The authors suggest that the women felt this way because breastfeeding was central to their “cultural identity as mothers” (2014, p. 145). Moreover, the studies found that breastfeeding was culturally significant for Black African HIV-positive women and the women felt that being a “good mother” was connected to breastfeeding her baby (Tariq, 2013, p. 275; Tariq et al., 2016, p. 1; Treisman et al., 2014, p. 145). Additionally, within the women’s communities, replacement feeding “signif[ied] their HIV status” (Tariq et al., 2016, p. 1) and women from African communities where breastfeeding is “culturally normative” indicated they would find it particularly difficult not to breastfeed (2016, p. 1). Further to this, within the women’s communities “the bottle-fed infant therefore functioned as a visible surrogate marker for an HIV-positive status” (2016, p. 3).

Influenced by the discussion above, I will reflect upon the ways HIV-positive women may *safely* mother their children and how this varies between different geographical locations. As I show in Chapter Six, this is because some HIV-positive women are advised to breastfeed their infants while others are encouraged to replacement feed them (WHO, 2010, p. 45; Dunn et al., 1992). Accordingly, it will become clear that living as an HIV-positive person who adheres to official advice may be entirely different in various geographical locations. The differences I am referring to here pertain to the requirements and effects of HIV (biomedical) interventions and prevention technologies on offer to people living with HIV in those locations.

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<sup>29</sup> Replacement feeding refers to the process of replacing breast milk with some other foodstuff (McAndrew et al., 2012). In Chapter Six I will elaborate on the definition and requirements of replacement feeding and explain how I have come to think of it as a technology.

Therefore, what matters are the various technologies, (bio) medicines and care that are on offer and the socio-historical and economic contexts and positions of people living with HIV in a particular geographical location. Additionally, however, what is or is not on offer, and the socio-historical and economic contexts and positions of people living with HIV in other geographical locations, also matters. For example, as Tariq et al. have argued, an HIV-positive mother in the UK who is strongly advised not to breastfeed may find it more difficult to adhere to her care practitioners' advice because she knows that HIV-positive mothers elsewhere are advised to breastfeed their babies (Dunn et al., 1992; Tariq, 2013, p. 275; WHO, 2010, p. 45).

### **The infallibility of biomedicine and biomedical technologies**

Moreover, the UK based qualitative studies position the care and (bio) medical technologies on offer in specialist HIV antenatal clinics as having the ability to prevent vertical transmission, if patients engage appropriately with them. This stance is not surprising, especially considering the following statement by the CDC:<sup>30</sup> “[w]hen HIV is diagnosed before or during pregnancy, perinatal transmission can be reduced to less than 1% if appropriate medical treatment is given, the virus becomes undetectable, and breastfeeding is avoided” (CDC, 2012, p. 1).

The role HIV-positive women play in prevention efforts are mentioned by the CDC only in relation to “prevention challenges” (2012, p. 2). They cite the following issues as being significant prevention challenges: “[s]ubstance abuse [...], [s]ocioeconomic issues [...], [l]ack of awareness that pre-chewing of food for infants is a transmission risk [...], and limited access to safe conception methods and services (for HIV-serodiscordant heterosexual couples)” (2012, p.2).<sup>31</sup> Thus, like Tariq, the CDC position the successful

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<sup>30</sup> The CDC is describing care in a resource rich location.

<sup>31</sup> The CDC is of course describing a situation specific to the USA. However, I cite the CDC here to draw out that the prevention challenges they mention are positioned as *coming from*

prevention of vertical transmission as having to do with HIV-positive pregnant women engaging with and accepting the care, medicines and technologies on offer *appropriately* (2013, p. 300).<sup>32</sup> ((Bio) medical) interventions<sup>33</sup> are thus situated as the solution to the problem of vertical transmission, if only HIV-positive women are able to access and appropriately accept them.

I understand the CDC's description of prevention challenges and the significance of biomedical medicines to be indicative of a concern expressed by many social scientific researchers over the pre-eminence bestowed upon biomedicine as the solution to the problem of HIV (Coates et al., 2008; Persson, 2013; Walby, 1996).<sup>34</sup> In relation to this, Nguyen and colleagues consider the conflicts between a desire to posit biomedical developments as the solution to HIV and one that is more able to embrace social issues (2011).<sup>35</sup> They argue that the idea that HIV is a medical problem that should best be dealt with using biomedical technologies is problematic (2011, p. 291) because

in the rush to paradigm shift, game-change, roll-out and scale-up yet a new set of acronyms and standardized interventions, local epidemiological, political, and socio-historical context is once again being ignored, surely only to resurface later as "culture" once much-heralded interventions fail to deliver. Holding out for a magic bullet — unlikely to ever come — diminishes interest in the hard, messy work required to enable social change and address the social inequalities and structural violence that drive this epidemic. Biomedical interventions are unlikely to live up to their promise if social determinants of access to

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the women and/or their socioeconomic position. Moreover, in 2010 the BHIVA/CHIVA guidelines writing group made a similar statement in relation to care in the UK (2010, p. 1).

<sup>32</sup> However, Tariq makes it clear that successful care extends beyond the prevention of vertical transmission. Nonetheless, social issues connected to the patients are positioned as standing in the way of prevention.

<sup>33</sup> The *interventions* would offer the mothers ways of feeding infants that did not involve breastfeeding.

<sup>34</sup> It is important to mention that these researchers are not specifically concerned with the problem of vertical transmission of HIV.

<sup>35</sup> Taken from: 'Remedicalizing an epidemic: from HIV treatment as prevention to HIV treatment is prevention'

prevention and treatment are not addressed (Nguyen et al., 2011, p. 292).

A focus on biomedical solutions becomes even more worrisome when considering the limited evidence that biomedical prevention is effective in “real-life conditions” (de Wit et al., 2011, p. 381). Thus, de Wit and colleagues bring up the important point that biomedical prevention efforts depend on the way in which people and their communities behave (2011, p. 381). Further to this, they remark that “[t]hese behaviors are shaped and constrained by the social, cultural, political and economic contexts that affect the vulnerability of individuals and communities” (2011, p. 381).

Referencing Flowers, Persson adds that “part of the attraction of the biomedical solution to the pandemic is that its apparent universality and simplicity can bypass the messy complexities of people’s lives” (2013, p. 1068). Like this, and for Flowers, the global HIV pandemic is fuelled by social, political and financial inequalities (2010, p. 2). Even so, Flowers argues that psychosocial and sociocultural understandings of living with HIV are becoming rejected and overlooked in preference for biomedical solutions that appear to be more straightforward (2010, p. 2).<sup>36</sup> Here it is important to consider that the authors of the UK based qualitative studies would be in more or less agreement with the arguments discussed above. Indeed the UK studies’ intention is precisely to gain a better understanding and draw attention to the significance of the “messy complexities of people’s lives” (Persson, 2013, p. 1068). Equally, however, is the fact that these studies acknowledge that there *is* an apparent biomedical solution to the problem of vertical transmission of HIV (CDC, 2012). Therefore, the stance taken by the UK based studies is to explore what is it about the “messy complexities of people’s lives” that makes them not able to accept the care and biomedical technologies that promise a solution to the problem (of the vertical transmission) of HIV (Persson, 2013, p. 1068). Thus, while the figures the

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<sup>36</sup> However, here it is important to mention that none of the social scientific studies mentioned here are specifically considering HIV in relation to vertical transmission in resource rich settings.

CDC (2012) present are clearly astounding, I argue that “the complexities [the prevention of vertical transmission are] embedded in and brings forth go beyond the scope of biomedicine” (van der Zaag and McKnight, 2016: forthcoming). Some of these complexities will be explored in the next section.

### **The consequences of care failures and the emotive experience of providing care**

Another important issue I would like to highlight in Tariq’s research is the emotive investment specialist practitioners make in order to provide their patients with care. Moreover, I will draw attention to the *care failures* that may be eclipsed by the UK antenatal clinics’ success at preventing vertical transmission. In order to do this, I will relay Tariq’s motivation to commence a PhD (Tariq, 2013, pp. 16-17). Her incentive for the study stemmed from her experiences as a medic working with HIV-positive pregnant women (2013, p. 16). Tariq and her colleagues felt that women living with HIV from Western Africa were singularly resistant to HIV care (2013, p. 170).

Tariq recounts an experience she had several years previously with a patient from Sierra Leone — Pauline — and cites her as the catalyst for her research (2013, pp. 16-17). She explains that Pauline had rejected specialist HIV antenatal care entirely and suffered a miscarriage as a direct consequence (2013, p. 17). Pauline said that the HIV specialist midwife had cursed her with HIV and thus caused the miscarriage (2013, p. 17). However, with tremendous effort, Tariq and her colleagues were able to entice Pauline to engage with care during her subsequent pregnancy, and she gave birth to a baby born free of HIV (2013, p. 17). However, after the baby’s birth, Pauline ceased to engage with HIV services for her own health (2013, p. 17). Finally, after years without receiving any care for her HIV, Pauline came into hospital with advanced HIV infection and was diagnosed with kidney failure (2013, p. 18). Nevertheless, as she was fearful that members of her church would see her attending HIV services, she refused any treatment and discharged herself from the hospital (2013, p. 18). Tariq explains that Pauline’s story was by no means unique (2013, p. 18) but her story did, however, remind Tariq that “HIV

pregnancy is embedded within a complex matrix of biomedical, social and cultural factors that are often poorly understood” (2013, p. 18).

Here I would like to emphasise that if we were to assess the care provided in the specialist clinic in relation to the serological status of babies born to mothers who received their care there, Pauline’s trajectory through the clinic would have been a success. After all, Pauline gave birth to a baby born free of HIV (Tariq, 2013, pp. 17-18). Thus, if we only consider certain aspects of her story, it could be viewed as further confirmation that specialist care and biomedical technologies are undoubtedly successful at preventing vertical transmission when patients engage with them. However, the baby born free of HIV was not the only *person* that was being cared for (or about) by the practitioners (and presumably Pauline) in the clinic. Instead, the baby that Pauline miscarried mattered to them, as did Pauline, her child, and her sexual partner(s). All of these *peoples’* wellbeing, deaths and/or possible deaths are *part of* and potentially eclipsed by one instance of *the successful prevention of vertical transmission*. By this I mean that specialist antenatal clinics may be (outwardly) assessed in relation to the prevention of vertical transmission of HIV, and not in relation to *interrupted pregnancies* (i.e. miscarriages and/or still births), patients’ and practitioners’ feelings or the future health of former patients. In other words, the unquestionable success of using treatment and care to prevent vertical transmission of HIV may belie the failures, deaths, struggles and suffering experienced by the patient, her family and medical practitioners. Therefore, Tariq’s experience with Pauline makes it clear that a baby’s serological status is not the only thing that matters.

The discussion above brings to mind an argument made by Nancy Scheper-Hughes about the significance of “public records” in her book, “Death Without Weeping: The Violence of Everyday life in Brazil” (1993, p. 292). Scheper-Hughes’ (1993) ethnography is relegated to two Brazilian towns in order to explore the effects extreme poverty has on maternity. In the course of that work, she makes the following observation in regards to the status of the information that becomes recorded in public records:

Public records [...] are obviously not “neutral” documents. They are not in any sense “pure” sources of data. [...] public records, count only certain things, not others. They count some things better than others [...]. They reveal a society’s particular system of classification. So they are not so much mirrors of reality as they are filters [...] (Scheper-Hughes, 1993, p. 292).

Thus the CDC’s report like the “public record[s]” presents a filtered version of reality (1993, p. 292). In other words, the reality presented by the CDC (2012)(i.e. 99% success rate at preventing vertical transmission of HIV), *filters away* the *failures* and the emotive experiences and consequences of providing care described by Tariq.<sup>37</sup>

Further to this, Tariq’s concern for Pauline is related to the often-mentioned fact that very little was actually known about Black (African) HIV-positive women in the UK’s experiences with antenatal care (Tariq, 2013, p. 201; Tariq et al., 2014, p. 59). The studies suggest that a problematic consequence of this is that the patients may have entirely different ways of understanding HIV and the requirements of care than do the medical practitioners. In other words, while the information the patient receives from the practitioners is of course not the only information that she would necessarily have access to, it is, however, the information that the practitioners would like to inform her behaviour. Although this does not mean that the practitioners’ information *does* necessarily dictate or influence the patients’ behaviour. However, and importantly, any other information or source of information that the patient might refer to (or be suspected of believing in) is positioned as potentially problematic, and therefore always suspect. Thus, the exact reasons why

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<sup>37</sup> Moreover, I argue that the practitioners may also function as filters. Thus, they sift through data (i.e. peer reviewed articles, official guidelines pertaining to the care and treatment of antenatal HIV, personal experiences of providing care and so on) and select the material they deem most appropriate to their patient cohorts’ medical needs and the patients’ (perceived) capacity to take on board information. Further to this, in this context a filter could be (part of) a technology; for example, when entering a term into a search engine the specific requirements and boundaries of that search engine will delineate the responses that are generated. Consequently, the responses generated would not necessarily reflect the available information related to the search term on the Internet or elsewhere. I will return to the concept of a filter in Chapter Four, where I use it to discuss viral load assays.

Pauline responded to care in the way that she did were not known by Tariq and this was a problem for her (2013).

Moreover, for Tariq, Pauline's time in the clinic also represents a failed opportunity to enhance her in the future. She argues that this is because specialist HIV antenatal care's additional significance is that it provides practitioners with an opportunity to entice women to participate in long-term care (2013, p. 201). Additionally, she contends, it is possible that "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" (2013, p. 201). In other words, specialist HIV antenatal care's *purpose* extends beyond the prevention of vertical transmission and attempts to enhance the patient (as she has the potential to be) in the future. However, Tariq argues that the specialist team's ability to ensure that their care fulfils its "promise" may be ruined by medical professionals in other fields (in her example specifically, maternity services) (Tariq, 2013, p. 294; Tariq et al., 2014, p. 59).

In this way, assessing the success of antenatal care based on whether or not HIV is transmitted to babies born to HIV-positive mothers fails to grasp the requirements and consequences of care for everyone involved. Thus, Tariq concludes her thesis by stating that her quantitative findings show that things are *not too bad* (2013, p. 294). Contrariwise, I argue that Tariq's story about Pauline illustrates how the findings she is referencing overshadows the fact that in the clinic the problem of HIV is not contained within the mother/pregnant woman and her bab(ies)' bodies. Consequently, the problem of HIV in the clinic cannot be resolved through biomedical interventions even if they can promise futures less affected by HIV. Instead, the problem of HIV in the clinic, as Tariq describes it, has the potential to extend beyond the possible transmission of HIV between mother and baby — to encompass and affect imagined futures and the feelings of both practitioner and patients and everyone else (potentially) involved.

And while Tariq et al. would undoubtedly agree with what I have written above, HIV specialist practitioners would also contend that biomedicine *does* offer a solution to the problem of HIV in the context of vertical transmission. This is because, for them, biomedical technologies and care are understood as having the ability to intervene into the “real” of the patient’s virus, as the practitioners imagine it to exist in the patient’s body prior to the technological interventions that *display* HIV (Rosengarten 2009; McKnight and van der Zaag 2015; van der Zaag and McKnight, 2016: forthcoming). However, while the practitioners would say that this is true, they would, as became clear above, also contend that the “problem of HIV” in the context of vertical transmission goes beyond whether or not the virus is transferred from mother to baby. The rest of the chapter will consider three broader themes that have emerged in the UK based studies in relation to theoretical literatures.

**How can we think about the significance of geographical place and movement between places?**

Thus far, it has become apparent that geographical place and origin matters, even if the exact ways in which they come to matter are obscure. Hence, while HIV is undoubtedly a global issue, the consequences are clearly different depending on where the person living with the virus *is* and comes from. Therefore, in addition to questioning the relationship between biomedical and social scientific descriptions of HIV, attention should be paid to how geographical locations would impact on these renditions and the way in which geographical space and the movement between spaces may impact on social aspects of HIV.

The idea of movement is especially pertinent to my work as I am looking at a clinical space in London that caters primarily to women who have moved and travelled tremendous distances. Following this, I question how we should begin to think about and clarify the significance of place and space, the effects of the movement of people between spaces, and the significance of the previous spaces that they occupied. In order to do this, I will begin to include

literatures that are more anthropological in their approach and methods. This is because, as Rayna Rapp has argued, anthropology is best at “show[ing] in lush empirical detail how national context, religious institutions and traditions, family formations, and cultural familiarity or distance really count in the making of scientific contexts” (2006, p. 420). And while my approach shares many components with ethnographic approaches, it is not a fully-fledged ethnography as it is understood within traditional anthropology (Hammersley and Atkinson, 1995). Instead, my research takes a qualitative approach that includes elements of observation, alongside the use of interviews.<sup>38</sup>

Flowers and colleagues remark on the way the expense or unavailability of HIV treatments in some countries means that an HIV diagnosis in those locations is tantamount to a “prognosis of death” (2006, p. 110). Furthermore, they argue that even in geographical locations where treatments and care are available, the meaning of an HIV diagnosis is variable (2006, p. 118). This is because of the risk of deportation that many HIV-positive people constantly live with and the complications that may arise from living with a chronic long term illness (2006, p. 118). These observations are important as they ask us to pay attention to the ways in which the circumstances of people living with HIV in the same geographical locations can vary drastically depending on, in their example, how resources and privileges (permanent residency and citizenship) are allocated or denied.

Furthermore, Heimer makes important points about the significance of geographical location and the import of paying heed to the specific circumstances that have made HIV/AIDS in sub-Saharan Africa different from HIV/AIDS in, for example, the United States of America (2007, p. 551). According to Heimer, it is primarily the social aspects of the disease that make it worse in Sub-Saharan Africa. Specifically, she writes that

[t]o be desperately poor, and HIV positive is very different from being comfortably well-off and HIV positive; to live in a country with a double-

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<sup>38</sup> I will expand upon my research methods in Chapter Three.

digit prevalence rate is much riskier than to live in one where fewer people are infected; to depend for life-saving drugs on foreign philanthropy makes access to treatment more precarious than it is in developed countries with imperfect) social welfare programs (Heimer, 2007, p. 552).

Her arguments are significant and I will extend them in this thesis by showing how inequalities experienced by people in specific geographical locations do not necessarily disappear if the people in question move to a different location. The point here is that the local cannot be easily separated from the global. People do not necessarily stay in the same geographic location. Moreover, there is constant movement between locations of information and (bio) medical technologies. Also, the implication of the various components connected to the pandemic in the various locations they might (temporarily) inhabit may change and be affected by their new environments.

I have found some of Didier Fassin's work useful when trying to think through these issues. Fassin's (2007, 2013) argument has precisely been to think of HIV and AIDS on a more geopolitical level, and, in the course of that work, he uses certain concepts that may be useful for understanding some of the apparent issues about the way these geopolitical questions seem to appear and disappear in the HIV social scientific literature as well as in the HIV specialist antenatal clinic.

For Fassin, AIDS in South Africa epitomises the nexus wherein the experience of life and the body in its entire social, political, historical and physical manifestations converge (2007, 2013). He considers the condition of "life embedded in the economic and social reality" as well as the experience of "life lived both individually and collectively" (2007, p. 226). Moreover, Fassin seeks to elucidate the "experience of the body" as it is embedded in the social contexts in which happenings occur, as well as the historical trajectories that have enabled them to emerge (2007, p. 226). He argues that an individual's experiences in the world "preserves the mark of the past, the past one lived oneself as well as the past experienced by the group to which one belongs"

(2007, p. 226). Although Fassin does not say this directly, an underlying idea behind this is that the person that he is concerned with is embedded within a particular location and subject to the possibilities ascribed to their bodies within that location.<sup>39</sup>

In the case of South Africa, for instance, the experiences of black South Africans living with HIV are directly related to the historical effects of apartheid. Moreover, Fassin argues that it is essential that an “AIDS patient’s experiences in South Africa cannot and must not be considered foreign to ‘us’” (2007, p. XV). In line with Flowers et al.’s previous argument (2006, p. 110), Fassin advocates for thinking of our shared humanity as not so much a matter of culture, but rather one that involves looking at historical facts that have led *us* to a position where we have different experiences and different “things” happen to our bodies as a result of differences in access to resources.

Applying Fassin’s arguments to the NHS specialist antenatal clinic means attention must be paid to the experiences of the clinic’s patients, and the contexts in which things happen to them. However, because the majority of patients have moved tremendous distances and are thus incorporated into a geopolitical framework, these happenings are diasporic in nature. Hence, what life is, as it is embedded in economic and social realities, may vary and be affected by the fact that these realities have changed for the person in question. After all, the patients cared for in the HIV specialist antenatal clinic in London have often been subjected to multiple economic and social realities. Which leads me to pose the following questions: “what is the experience of the body when it is pregnant and what are the contexts in which things occur to the pregnant body?” Moreover, “how do we think about the historical

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<sup>39</sup> These sentiments are echoed by Farmer (2004) who argues for the importance of informed historical and political knowledge when trying to make sense of AIDS epidemics in the postcolonial world, and Ridge and colleagues (2007) who remark upon the stark difference between access to HIV resources and information between white gay men and non-white HIV-positive people in the UK. Moreover, Crane argues for the significance of considering and understanding the effects of poverty and marginality when conducting AIDS research (2002).

trajectories that have enabled these things to occur?" The answers to all of these questions are bound to be multiple, and the way in which the answers might interact is undoubtedly complex.

While Fassin's analysis touches on geopolitical concerns, his framework is tied to a specific geographic location and is what he has accordingly termed a "vertical ethnography" (Fassin, 2013, p. 120; Hansen, et al., 2013, p. 117). Fassin uses the term to describe ethnographies that study a given society on "several levels" or "places" (2013, p. 120). He claims that vertical ethnographies uncover a multitude of perspectives within the given society (2013, p. 120). Moreover, Fassin argues that one of the strengths of a vertical ethnography is in the level of detail a researcher is able to amass regarding their location of interest (2013, p. 120). An underlying assumption in his definition of a vertical ethnography is that the "levels" or "places" (2013, p. 120) wherein the society under scrutiny moves, will remain confined within a country's borders. In this way, Fassin freely moved around South Africa collecting data. He did not, for example, limit his enquiry to one township or province; neither did he follow his research participants as some of them moved outside of South Africa. The way Fassin collected data within South Africa becomes remarkable when thought of in relation to his description of horizontal ethnographies. Fassin contrasts vertical ethnographies with horizontal ones which he argues have a "geographical extension", and are (although he does not say so directly), therefore not equipped to "reveal a diversity of perspectives" (2013, p. 120). He presents a study by Nancy Scheper-Hughes' as an example of a horizontal ethnography and thus her study is used to exemplify the limitations of this kind of ethnography (Fassin, 2013, p. 120).<sup>40</sup>

While respectfully acknowledging Fassin's contributions to my thesis, I take issue with his critique of Scheper-Hughes's work and the way he distinguishes between horizontal and vertical ethnographies. My concern is threefold: firstly, Fassin's arguments in regards to the superiority of a vertical ethnography

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<sup>40</sup> The article in question is called "*Parts unknown: Undercover ethnography of the organs-trafficking underworld*" (2004).

presuppose that ethnographers will be more fruitful if they place a geographical limit on their area of enquiry. By default, Fassin is thus proposing a country as an appropriate field of enquiry. This is problematic especially when considered in relation to the following statement he makes in regard to a reviewer's critique of his book *When Bodies Remember Experiences and Politics of AIDS in South Africa* (Fassin, 2007):

I contend that one should not have to choose between the sufferers or their relatives and the activists or the sociologists, the private worlds of patients and the public scenes of politics and science: it is in the confrontation of these critical social spaces and those who inhabit them that a deeper understanding of the larger picture becomes possible (Fassin, 2013, p. 121.).

Here I question whether or not it would be possible to adhere to Fassin's contention if the ethnographer discovered that some or all of the actors named above (i.e. sufferers, their relatives, sociologists, private worlds of patients, public scenes of politics and science) were connected to or *part of* places outside of South Africa (2013, p. 121).<sup>41</sup> Fassin's argument implies that if the ethnographer were to *follow* them outside of the boundaries of a country and consequently engage in a horizontal ethnography, the ethnographer's ability to capture a diversity of perspectives would be inhibited. Therefore, Fassin's promotion of a vertical ethnography is problematic because it imposes restrictions on how far the ethnographer should go in tracing *what matters* and how bodies come to matter. Thus, while Scheper-Hughes writes that her ethnographic method was to "follow the bodies" (2004, p. 32), Fassin is suggesting that it would have been more fruitful had she stopped as soon as the bodies appeared to cross borders.

Secondly, Fassin's suggestion that his study is relegated to South Africa is in fact misleading. Thus, while most of his research participants and the locations he conducts fieldwork in are undoubtedly South African, their circumstances and the conditions unto which they exist are entirely connected to places outside of the country. As Fassin points out himself, the HIV

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<sup>41</sup> For example, a sociologist could simultaneously be in South Africa conducting fieldwork while also being part of a research institution in Europe.

epidemic in South Africa, for example, is connected to the HIV epidemic in other countries (2007, p. 75).

Finally, Fassin's critique of horizontal ethnographies risks diminishing his own vertical ethnographies' value. This is because Fassin is suggesting that smaller geographical areas by default garner richer data and more in-depth enquiry. If this were true, why stop at the borders of a country? Why not be more specific, more local? Why not investigate a township, or an area within a township, a house, or a bedroom? Further to this, does a geographical extension to an ethnography always pertain to countries? If it does, would this make research on the migration patterns of, for example, South Africans between neighbouring countries less ethnographically rich than a study that considered the migration of South Africans within South Africa? Who decides if the unit of analysis is too large or too small to produce evocative and meaningful data? Moreover, I question the usefulness of positioning vertical or horizontal ethnographies as being better or worse than the other. Surely, any ethnography, or research for that matter, should be assessed in relation to what it finally accomplishes and not the boundaries of the location wherein it took place?

Further to this, my research would not fall neatly into either of Fassin's categories. Therefore, while my unit of analysis was small, both in terms of its physical space and also in terms of the amount of people that regularly frequented it, the patients in the clinic were so unmistakably and intrinsically connected to geographical locations which were far away from the clinical space, that I could not ignore this. In this way, it is the moments when there appears to be a conflation between local and global, privilege and disadvantage, that I became interested in investigating further. Thus, the inequalities have to do with more than just differences in the availability of certain biomedical technologies and care options within or between different geographical locations. Rather, the differences have to do with the way in which certain groups of people will have better care than other groups of people, wherever they are (Flowers et al., 2006, p. 119). In what follows, I will

introduce the concept of an HIV diaspora and explain how I would like the term to be understood and used.

### **HIV Diaspora**

One of the persistent hesitations in this thesis is this broader picture: the inequalities that exist between the HIV-positive pregnant women cared for in the specialist antenatal clinic in London and HIV-positive women elsewhere. These geopolitical concerns have been an abiding anxiety and question of mine, although they are not obviously articulated in this way in the space of the NHS specialist HIV antenatal clinic.<sup>42</sup> As mentioned previously, in this thesis I am concerned with a clinic located in a country where HIV is a chronic illness. However, the clinic caters mainly to people originally from locations wherein HIV-positivity would signal a life-limiting condition. Thus, my empirical material deals with people that have moved through different geographical spaces and (political) economies. In this way, it became clear to me that despite the clinic's location and its associated privileges, its patients' movement through (and experience with) multiple geographical locations transformed the clinical space into a geopolitical one; traces of these issues take shape in the interactions between the healthcare providers, the patients and myself.

The majority of the clinic's patients were thus immigrants, and while some of them had become British and/or had permanent residency in the UK, they were (as will be explored in later chapters) all indelibly and intricately connected to their countries of origin. Moreover, the connections were always significantly affected and amplified by (various issues related to) HIV and the meaning, consequences and effects of the virus in their countries of origin *and*

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<sup>42</sup> However, it is important to mention again that an awareness of the significance of past geographical locations is readily acknowledged amongst the HIV practitioners. Thus, Erwin and Peters (1999) argue for the importance of taking the particular concerns of Black Africans living with HIV in the UK into consideration, if care efforts are to be improved for this patient group. And Doyal and Anderson (2005) provide an evocative assessment of the experiences of HIV-positive African women living in London, which highlights the importance of the women's culture, religion and communities. Moreover, and as discussed previously, Tariq sites the significance of an African diaspora (2013).

in the UK. Following this, I wanted to find a term that would both allude to the experience of geographical movement (of individuals and groups) between locations wherein HIV and death are *coupled* to locations wherein they are not. Therefore, I have chosen to speak of an HIV diaspora and the women who are enveloped within the diaspora, to refer to this phenomenon. I will subsequently demonstrate throughout this thesis how the diasporic HIV-positive women involved in this research are connected to and affected by the vicissitudes of HIV in multiple geographical locations.

Moreover, my attraction to the concept of diaspora is tied to the term's unequivocal connection to postcolonial studies where it is consequently explicitly and unapologetically about power, location, race, (post)colonialism and gender (Clifford, 1994, pp. 313-314). In regards specifically to gender, Clifford makes the interesting observation that for women, the experience of diaspora may both reinforce and also weaken "gender subordination" (1994, p. 314). Additionally, by using the term diaspora, I invoke the three core elements that Brubaker argues are often considered integral components of a diaspora (2005, p. 5): namely, "dispersion in space", "orientation to a 'homeland'" and finally, "boundary-maintenance" (Brubaker, 2005, p. 5; Clifford, 1994, p. 305; Safran, 1991, p. 83; Tölölyan, 1996, p. 14).

However, I acknowledge that my use of the term does not neatly fall within its traditional meaning or common usage (Clifford, 1994, p. 306). Thus, I argue that the HIV-positive pregnant women involved in this study were incorporated within an HIV diaspora. Hence, what they have in common is that they moved (or had been moved) across geographical spaces, and they are all in some way still connected to a homeland. It could be that they have left behind children or that the experiences they had in their homeland were so deeply affecting that they will be forever emotionally connected to their previous location. Finally, in regards to boundary maintenance, the HIV-positive women involved in this study occupy an interesting position. Within diaspora studies the act of boundary maintenance is usually understood of as pertaining to either various kinds of self-segregation and/or forms of social exclusion (Brubaker, 2005, p. 6). And while this may also apply to women incorporated

within the HIV diaspora, in their case, boundary maintenance likewise pertains to their HIV, or rather, the methods that are used by health care practitioners, the women and their families and communities to come to know, detect and contend with their virus. Accordingly, in Chapter Four, I will explore the ways in which viral load assays are implicated in the maintenance of an HIV diaspora. In Chapter Five I will provide several examples of how a patient's diasporic position may disrupt the provision of care in the clinic. And finally, Chapter Six will consider how various methods of feeding infants have particular significance for women within the HIV diaspora.

In relation to the above, these chapters will consider who/m might benefit from various HIV interventions and will include an assessment of the way in which some HIV interventions may simultaneously appear to promise *futures less affected by HIV*, while also providing *futures affected by other kinds of HIV*. As I will discuss in Chapter Six, replacement feeding assures prevention of HIV transmission through breast milk, but it may also reveal the mother's HIV and thus expose the infant to the stigmatising effects of HIV/AIDS despite the fact that the infant has been born free of the virus. Consequently, I will argue that babies born to HIV-positive mothers may be marked by the stigma of HIV/AIDS that is enacted within the infant's family (van der Zaag and McKnight, 2016; forthcoming). This discussion will also make clear that the (imagined) benefits of any intervention or technology should be considered in relation to the intervention's possible adverse effects on the lives of people affected by HIV.

Henceforward, it will become clear in these chapters that various technologies and people are involved in the act of maintaining HIV diaspora boundaries. Consequently, it will become apparent that there is a disconnection between the real of HIV (as it may or may not be inside a person's body) and its stigmatising effects on the bodies of HIV-positive and HIV-negative people. Again, I use the concept of "the real" to refer to the way in which the virus is imagined by the practitioners to exist in a host's body prior to the technological interventions that *display* HIV (Rosengarten, 2009; McKnight and van der Zaag, 2015, pp. 135-136).

However, the UK based qualitative studies discussed earlier drew attention to the fact that the women living with HIV might have significantly different ways of understanding HIV (and associated intervention and technologies) than their clinic care providers. Therefore, in what follows I will explore the question of “what is HIV” within the clinic. I have found the work of Annemarie Mol useful when trying to investigate this question. This is because one of Mol’s primary concerns has been to discover what a (specific) disease is within a clinical environment.

### **Doing HIV in the clinic**

Up until this point, it has become clear that I am concerned with a disease, with pregnancy, practices of care, and with the unequal access to biomedical technologies which is apparent within the HIV/AIDS pandemic. Moreover, the discussion of the UK based qualitative literature above made it clear that very little is known about Black (African) HIV-positive pregnant women’s experiences with care or their understanding of HIV. Following this, I have found the work of Annemarie Mol to be useful for understanding what HIV *is* for practitioner and patient, as well as how its identity is maintained within the clinic and the requirements of the care that are provided to HIV-positive pregnant women. More specifically, *The Body Multiple: Ontology in Medical Practice* (2002), and *The Logic of Care: Health and the Problem of Patient Choice* (2008) are particularly valuable when thinking about HIV and pregnancy. Her other book, *The Body Multiple: Ontology in Medical Practice*, is an “ethnography of disease” (Mol, 2002, p. 151) written from the perspective of medical practitioners and the technologies, methods and methodologies they use. What is of particular relevance for me is how Mol (2002) questions what a disease is within a clinical environment, and thus, she provides me with the tools to do the same. Before I expand upon her work, I will briefly discuss some of the theoretical ideas that inform her thinking.

While Mol's approach comes from a version of STS, it is important to consider what John Law and others have argued — namely that there is no unified field that we could call STS (Law, 2008). Instead STS consists of multiple, sometimes competing, theoretical impetuses.<sup>43</sup> However, Beynon-Jones points out that much of STS's theory shares a united analytical incentive which consists of “the de-centring of human agency and the acknowledgement of the live-likeness of the nonhuman world” (Beynon-Jones, 2013, p. 107).

Similarly, one of STS's primary contributions to my way of thinking about HIV and the clinic is the argument that both science and technology are entirely social and active processes (Latour and Woolgar, 1986; Berg and Akrich 2004, p. 2) which are not natural in and of themselves. Following this proposition it becomes clear that there is not, nor will there ever be, a scientific or technological method in existence that is able to “interpret” nature and produce knowledge thereby to uncover an elemental truth about the world (Berg and Akrich, 2004, p. 3). This position, Berg and Akrich argue, enables STS to completely refuse to make any hypothesis about the nature of the objects it studies (Berg and Akrich, 2004). On the contrary, it considers “nature” as an empirical question (Berg and Akrich, 2004). By this, they mean that because STS does not fundamentally believe that there is a particular way of knowing a truth about an object and it does not assume a pre-existing truth prior to what is produced by interactions within a particular network (Akrich and Pasveer, 2004, p. 65), it is therefore only possible to investigate the ways in which the object comes to be known and enacted (Berg and Akrich, 2004, p. 3).

The version of STS that I am concerned with here involves an approach in which no kind of body is positioned above the other. Neither the body, as it is experienced by an HIV-positive pregnant patient, as it is understood by health care practitioners, or as it is seen through various biomedical technologies, is prioritised over others. Rather, this tenet of STS tries to follow the complexities of all of these bodies by “describing how each one is specifically

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<sup>43</sup> When I refer to STS, it is with the caveat that I am not speaking about all versions of STS.

connected to a set of practices, material devices and rhetorical genres which include modalities defining the way it relates to other bodies” (Berg and Akrich, 2004, p. 3). Following this, the significance of the location wherein empirical material is gathered becomes clear. This is evident if we consider the different circumstances that would inscribe an HIV-positive pregnant woman in a location where HIV and death have been decoupled (see Rosengarten 2009, p. 3), versus an HIV-positive pregnant woman in a location where HIV is an inevitable precursor to death. It becomes clear that what the body of the HIV-positive person is (and may become) in these diverse locations may be entirely different. Further to this, the effects of any particular rendition of the body would presumably be different depending on who is asked about it. By this I mean that the experience of being a patient in the antenatal clinic versus the experience of being a medic caring for that patient would ostensibly be different. Further to this, the perspectives of patient and practitioner would be different from a biomedical, and/or assessment technologies’ rendition of the body, or parts of the body. In other words, the various ways that HIV is done in different geographical locations and from different perspectives enable different and “ontologically multiple” kinds of bodies affected by HIV (Mol, 2002).

Indeed, for Mol, it is the actions taken by the medical practitioners that are of theoretical interest (2002, p. 152). She argues that her ethnography’s concern with the specificities of medicine “is its force but also constitutes its limits” (2002, p. 26). She distills atherosclerosis the disease (as it is evidenced by and through medical practice) from the experience of being a person diagnosed with atherosclerosis.

It is possible to say that in practices objects are *enacted*. This suggests that activities take place- but leaves the actors vague. It also suggests that in the act, and only then and there, something *is* - being enacted. [...] Thus, an ethnographer/praxiographer out to investigate diseases never isolates these from the practices in which they are, what one may call *enacted*. She stubbornly takes notice of the techniques that make

things visible, audible, tangible, knowable. She may talk bodies — but she never forgets about microscopes (2002, pp. 32-33) (Emphasis in original).

Moreover, Mol argues that the object does not pre-exist its own enactment. Or in other words, objects are real only if they are part of practice. By her definition, the object *is* “a reality enacted” (2002, p. 44). As a result of disease being enacted in practice, she argues that it is possible for the *same* disease to be *done* differently in different environments (2002, pp. 35-36; Law, 2009, p. 152). Mol claims that the differences depend on the varying requirements of the locations and the actors involved in the object’s enactment. In other words, the same object can therefore be entirely different. In relation to this, Beynon-Jones argues that Mol’s main argument is that “the real is relationally enacted in [socio-material] practices” and that “if those practices were to change the real would also be done differently” (Beynon-Jones, 2013, p. 107). Thus, as mentioned above, bodies are ontologically multiple (Mol, 2002, p. 46), and so if the object is HIV, what HIV *is*, and the effects that it has, are particular to the environment wherein HIV is enacted.

Here it is important to stress that Mol would not say that HIV becomes a material reality only if and when it is enacted. For example, a person with undiagnosed HIV will still be subject to the progression of the disease, although the pathologies experienced may be attributed to some other malady.

Mol’s exposition opens up the possibility of considering what the effects of multiple objects may be on, for example, antenatal HIV prevention methods, both within the space of the clinic and external to it. In other words, what antenatal HIV interventions constitute might vary depending on what HIV is within the environment wherein the interventions take place. Following this, HIV-positive pregnant women and their unborn babies would be significantly affected by the way HIV is enacted within the space where they receive their care. According to Mol, the variations in the discernment, reading and interpretation of the virus correspond to what are effectively *multiple viruses*

— that is, different ontological accounts which would each have corresponding ways of being acted upon, and enacted by the practitioners and their patients. In other words, a patient's body and disease may be *done* differently. Furthermore, her arguments suggest that a patient's virus would *not* pre-exist its enactment through practice.

While Mol's approach has been hugely influential, it is not without its detractors. One of the main criticisms directed towards her work is that it fails to adequately acknowledge the researcher's role through the act of conducting research (writing and theorising) and how it is an integral part of the "intervention" that is being observed (Gad and Bruun Jensen, 2010). However, I will provide my own critique of the *Body Multiple* later in this chapter and in relation to her other book, *The Logic of Care* (2008).

#### **HIV and pregnancy: things are getting more complicated**

Successful HIV care depends on a patient's compliance to care, for the reason that the patient must participate in care for it to work. The patient must, for example, come to her appointments and take ART, concede to various interventions such as having a caesarean section and she must answer questions the practitioner deems to be significant. Therefore, after the initial diagnosis of HIV-positivity and confirmation of pregnancy, the requirements of successfully preventing vertical transmission concern the particular care on offer, i.e., the logic of care in the clinic, which in this instance require that the practitioners must encourage the patient to speak about her life and of her experience of the care she is receiving. These narratives are considered crucial to the prevention effort. This is because the practitioners know that the patient's feelings and experiences may disrupt care; for example, a patient who hates coming to the clinic may be less likely to regularly attend her appointments and a patient who believes that prayer alone may cure HIV might not conform to the practitioners' plans for her care (Doyal and Anderson, 2005, p. 1736). Thus, the practitioners know that patients who are experiencing difficulties in their lives outside of the clinic will find adhering to

treatment regimes more onerous (Tariq, 2013, Doyal and Anderson, 2005; van der Zaag and McKnight, 2017: forthcoming). Further to this, the patient's narrative would assist the practitioners in determining how to work with patients who are resistant to care. The practitioners would have different approaches depending on, for example, if the patient's reluctance (was thought by the practitioners) to concern her religious beliefs, depression, psychosis, lack of family support, and so on. Importantly, the practitioners would need the patient to speak about her life in order to establish what influenced her hesitancy.

Consequently, while HIV can be *done* (in the way that Mol writes of *doing* disease), without the perspective of the HIV-positive patient it cannot be *treated* and vertical transmission cannot be prevented without the patient's participation. Following this, an ethnography of HIV and pregnancy requires that the ethnographer also consider the perspective of the patient, being that it is an inherent and crucial part of care and prevention. As can be seen in the quote below, Mol makes an allowance for this; that is, the inevitable complications that follow if an ethnographer expands her scope of interest to include multiple objects.

If one begins to study the interferences between the enactments of two or three multiple objects (such as atherosclerosis *and* sex difference), then the complexities start to grow exponentially — though these are complexities to be investigated elsewhere, for this is the point where this study stops. It has done what it set out to do. A single/multiple disease has been described as a part of the practises in which it is enacted (Mol, 2002, p. 151)(Emphasis in original).

Encouraged by Mol's invitation to investigate these complexities elsewhere, this study seeks to explore some of them. A first step in doing this is to think about the kind of woman that *presents* herself (or is presented to) for diagnosis in an HIV specialist antenatal clinic in London and the kind of care she requires. To begin, the primary goal of the specialist antenatal clinic is to manage the pregnant and postnatal patients' HIV and health, while

simultaneously preventing vertical transmission. Moreover, while the unborn baby is not legally a patient in its own right, and is therefore not a subject of care, the future baby's health is of primary concern.<sup>44</sup>

Accordingly, the practices in which the practitioners in the clinic engage are intrinsically concerned with the issue of time as it relates to their patient's pregnancy. By this I mean that they must consider the patient, as she is when she first presents herself in the clinic *and* as they expect and/or hope she will become throughout her pregnancy and postnatally. Therefore, in addition to their own, and their patient's expectations and desires for her unborn bab[ies], they must take into consideration the subjectivity and health of the baby/babies (that will hopefully be) born to their patient, especially so in cases where vertical transmission is considered to be particularly difficult to prevent.

Moreover, I argue that the combination of HIV and pregnancy (as perceived by the practitioners) require that they consider the feelings they think their patient and their offspring may have in the future when making decisions about care in the present. This is particularly significant because it alludes to some of the complexities that may occur in the specialist clinic if a pregnant patient resists or refuses the practitioners' desired care plan. From the practitioners' point of view, a patient's refusal to comply with their care plan may make it impossible for the patient and her (unborn) baby to achieve what they imagine is their potential in the future. In other words, a patient's noncompliance may endanger the patient's and her (unborn) baby's future. Thus, while the pregnant patient is legally autonomous and has the right to concede to or refuse care, her unborn baby is not and cannot. Consequently, I argue in later chapters that the practitioners advocate in the present on behalf of the (unborn) baby and the mother as they imagine them having the potential to become in the future. It is the unborn baby's promise of a future free from HIV, and the practitioners assumption that the postnatal patient will be happy that prevention occurred, that changes the way the pregnant

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<sup>44</sup> Vora (2013) makes a similar argument in relation to assisted reproductive technologies in India.

patient's autonomy is conceived of and dealt with in the clinic, prior to the baby's birth.

In regards to this, Mol explains that a vascular surgeon in one of her hospitals of interest makes an assessment as to whether or not invasive treatment may be appropriate based on his patient's specific circumstances at that moment in time (2002, p. 72). Inversely, I argue that the practitioners in the HIV specialist antenatal clinic base their care decisions on the patient as she is now *and* on how they hope she and her baby will become in the future. Hence, they are consulting with a real present-time patient, with her future self, and with her future baby, as they *imagine* them to have the *potential* to become if care is successful.

In other words, the practitioners are charged with the task of trying to envisage and contend with the future, i.e., with the patient and her offspring as they may or may not become, as a result of the biomedical innovations and care the present-time patient engages with or rejects. It will become clear in my empirical chapters that the future patient, or rather, the future patient and her HIV — (negative or positive) future baby — play a significant role in the care made available to the “present-time pregnant patient”, as do ideas about the kind of behaviour *good* (becoming) mothers ought to engage in. Although it is not spoken of in this way in the clinic, I will illustrate in chapters Four and Five how the practitioners explore and anticipate the possibilities of the biomedical technologies and care on offer in the clinic in relation to their patient's (real and imagined) behaviour. The patient's (real and imagined) behaviour becomes accessible to the practitioners through their interpretation of the patient's behaviour and narrative.

Many of Mol's arguments are useful to me in that they ask us to question how an object comes into being within an environment and to investigate how the object is maintained, negotiated and coordinated within that space. In this way, informed by my experiences in the clinic and my understanding of the requirements of HIV, pregnancy, the clinic and its patients, I intend to further Mol's arguments in this thesis. Moreover, I will question what significance the

care on offer in the clinic has for the patients. These are all concerns that will be investigated throughout this thesis in relation to what the patients and practitioners told me mattered to them. To assist this, the next section will concern Mol's articulations on the logics of care that she argues might be available to patients.

### **The logic(s) of caring for the imagined patient**

In *The Logic of Care*, Annemarie Mol questions the implications of the apparent shift within healthcare that attempts to “increase the possibilities for patient choice” (2008, p. xiii). She challenges the widespread assumption that “care” is a “soft form of force”, and claims that within the healthcare field “good care” as an ideal suffers from the elevated position of patient choice (2008, p. xxi).<sup>45</sup> Mol contends that although the ideal of patient choice appears to be an attractive alternative to care, it is not often able to fulfil its promise of improved care. She explains that this is because the tenets that inform patient choice — or rather the rational that informs (in her words) the “logic of choice” — reduces the care on offer (be it a technological device or emotion such as kindness) to a rigidly bounded product that may be chosen or not (2008, p. 18). Conversely, Mol argues that within the “logic of care”, care does not have defined boundaries and is thus “an interactive, open-ended process that may be shaped and reshaped depending on its results” (2008, p. 20). According to Mol, this capability is more conducive to the unpredictability of diseased bodies. In relation to this she writes:

even though care is result-oriented, it is not necessarily bad when “health” and a “good-life” remain out of reach. Some diseases can never be cured, some problems keep on shifting. Even if good care strives after good results, the quality of care cannot be deduced from its results. Instead, what characterises good care is a calm, persistent but forgiving effort to improve the situation of a patient, or to keep it from deteriorating (2008, p. 20).

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<sup>45</sup> In this thesis I will write about caring care, which I define as good care in practice and which retains the ideal of good care, as Mol has defined the concept.

Following this, she contends that the two logics are often incompatible and “good care” as an ideal suffers not only from the elevated position of “patient choice” (2008, p. 1) but also because “patient choice” “alters daily practices in ways that do not necessarily fit well with the intricacies of our diseases” (2008, p. 2). Accordingly, practices that are intended to encourage the expansion of the ideal of patient choice conversely “erode existing practices that were established to ensure ‘good care’” (2008, p. 1).

Mol uses a personal example to illustrate the differences between the logic of care and the logic of choice. She describes a situation where she decided, on advice, to undergo an amniocentesis in order to establish the viability of a pregnancy (2008, p. xi). In response to the concern she expresses about the procedure, the nurse in charge tells her “it is your choice” — the insinuation being that Mol would be responsible if the outcome were negative and she lost her pregnancy (2008, p. xi). The implication is that Mol should weigh up the pros and cons of the procedure and make her own decision about whether or not to proceed with it. Mol argues that she is thus empowered by having the ability to choose while simultaneously being isolated (2008, p. xi.). Hence, she contends, the boundaries of the product on offer do not include, for example, a kinder, more supportive interaction with the practitioner (2008, p. xi). Here, it is important to clarify that the product on offer consists of both the amniocentesis *and* the nurse and her care. Following this, Mol gives examples of what the nurse might have said that would have been conducive to a logic of care, rather than one of choice.

She might have touched me in a kind way. And she might have used the moment to encourage me to behave [...] But instead she illustrates beautifully how mobilising the logic of choice can lead to poor care. It can shift the weight of everything that goes wrong onto the shoulders of the patient-chooser (2008, p. xi).

Here I would like to consider the act of weighing up the pros and cons of the procedure in relation to the *Body Multiple* (2002). Would Mol’s feelings about the procedure have been *heard* if she had been one of the patient participants

in that study? Mol was concerned because the procedure carried a (small) risk of having a spontaneous abortion (Mol, 2008, p. xi). Mol's concern over the procedure *happened* prior to the amniocentesis becoming enacted in practice. Moreover, Mol's thoughts (i.e. the possibility of having a baby with Down Syndrome, her "healthy child", and the already challenging demands of balancing parental and work responsibilities) were integral to her decision to have the procedure (2008, p. xi). Thus, they informed her behaviour in the clinic, while still remaining unarticulated in the clinic.<sup>46</sup> Instead Mol's unspoken thought processes are only *heard* long after the procedure was enacted in practice because Mol chose to write about them in a book. In line with my argument, Mol explains that had the nurse behaved in a way that reflected a logic of care, the nurse would have been attuned to the fact that a patient might have an internal conflict prior to engaging in a medical procedure. In other words, the nurse would have been aware of the significance of the patient's unspoken feelings, even if those feelings do not ultimately *get in the way of* the practitioner's plan for care. Accordingly, the nurse would address the concern Mol did not articulate. To do this the nurse would have needed to anticipate a patient's trepidation and behave empathetically even if a patient does not show signs of or voice unease.

To reiterate, Mol's thoughts were part of the enactment of the amniocentesis — that is, her thoughts were enacted in practice. This is because her thoughts took place prior to the amniocentesis being enacted in practice. However, while Mol's unspoken thoughts were enacted in practice they are only distinguishable to us because she chose to write about them long after the procedure took place. Her thoughts would not have been apparent to us if we had been the nurse or an ethnographer observing or taking part in the

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<sup>46</sup> Prior to the procedure being enacted in practice Mol makes the following statement to the nurse: "I hope it all goes okay" (2008, p. xi). Thus, she does voice concern before the procedure took place. However, my point is that her statement does not indicate what her exact fears were (i.e. spontaneous abortion vs. giving birth to a baby with Down's Syndrome and the effects this might have on her child and work). Thus Mol's statement to the nurse did not reflect the reasons why she was uneasy, or her concern over the effects the procedure and/or an *unhealthy* baby might have on her child and work.

procedure (as Mol has described the role of an ethnographer in *The Body Multiple* (2002)).

Thus, Mol's internal debate is only heard long after the procedure, even though it ostensibly took place because she had this internal debate. Therefore, while Mol's thoughts — about her child, her work, and the effects that a baby with Down Syndrome might have on her already challenging work-life balance — were integral to her decision to go ahead with the procedure, her thoughts would not have been evident to Mol the ethnographer/author if she had been a patient participant in that study. Rather, within that study a patient's thoughts are overlooked if they were unspoken at the time when the procedure (being observed by the researcher) was enacted in practice. Conversely, within *The Logic of Care* (2008) Mol posits a patient's internal conversation as being crucial to the way in which she has chosen to describe the differences between a logic of care versus a logic of choice (2008, p. xi).

To reiterate: patients' unspoken feelings about a medical procedure (or anything else) would not become apparent in *the Body Multiple* (2002), but these feelings are, according to Mol, integral to good care.<sup>47</sup> Moreover, patients' unspoken thoughts about a medical procedure may, according to Mol's narrative, become hugely significant in the future. In her case, the feelings she had about the amniocentesis prior to its enactment in practice become integral to her arguments in the *Logic of Care*. It is possible, however, that another patient might not respond to her concern in way that is so productive.

Nonetheless, a patient's unspoken feelings about a medical procedure or care clearly have the potential to matter in unpredictable ways in the future. By this I mean that the unspoken has potential to matter in the future in ways that could not be anticipated in the present. For example, the nurse caring for Mol

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<sup>47</sup> I am not suggesting that Mol is saying that a patient's thoughts are not important. Instead, Mol's argument that reality is enacted in practice entails that the patient's thoughts would be part of whatever became enacted in practice, although, as I have argued, these thoughts would not necessarily become apparent to the practitioners or the researcher.

could not have predicted that she would have been mentioned in a book written by her in the future, even though Mol's feelings, which later informed the book, were *part of* what became enacted in practice. Thus, the unspoken may be enacted in the future in ways that bear no obvious relation to their enactment in the past or present. I will consider these arguments further in Chapter Five when I discuss the way the practitioners fear that a patient's past experience with health care may influence her behaviour in the present and future.

Accordingly, in Chapter Five I will argue that the practitioners believe that a patient's feelings about her experiences with care in the past have the potential to influence the patient's engagement with care in the future. A patient who, from the perspective of the practitioners, behaved as an ideal patient (i.e. accepting of all interventions and forthcoming with information the practitioners required) may, if she falls pregnant again, rebel completely against the practitioners' desired plan of care. According to the practitioners, the impetus of her rebellion could be unarticulated feelings that she has in the present about HIV or the care that was provided to her in the past. Encouraging the patient to speak about the things the practitioners feel may be relevant to her care (in the present and future) is the only way that they feel they can prevent these potentially disastrous imagined futures from becoming enacted in practice.

Returning to *The Logic of Care* (2008), the variable in Mol's example is the nurse and her behaviour, not the patient's person or positionality. However, both of the logics that Mol is describing become much more complex and problematic to envisage in practice, if the patient is the variable. We may consider Mol's ideas further by questioning whether patients with temporary or conditional access to advanced biomedical technologies and care would be situated differently from patients who have no access or patients who have unfettered access. Following this approach, the effects of different *kinds* of patients' incorporation into any logic might vary significantly. Consequently, and in relation to my work, the positionality of the patient outside of the clinic

as she is located prior to being incorporated into either “a logic of care” or “a logic of choice”, should be considered (Mol, 2008).

Underlying Mol’s argument is the proposition that patient choice will not bring about desired improvements in healthcare and that the introduction of patient choice will not ultimately make *space* for patients. She claims that it would be advisable to try and “improve care on its own terms” without provoking it by “dreaming of choice” (2008, pp. 2, 73). Instead, her aim is to “articulate the specificities of good care so that we may talk about it” in order to protect it, for, as she argues, good care is under threat (2008, p. 2).

Furthermore, Mol writes that initially choice is perceived as being good because it “offers individuals autonomy” and promotes equality (2008, p. 74). However, beyond this initial perception, at the point at which patients may be expected to make life and death decisions, in their choice of treatment options for example, it becomes clear that the logic of choice avoids providing guidance, since the patient is expected to “attach their own value to just about everything” (2008, p. 74). However, Mol contends that such autonomy does not truly exist, and any choice that the patients make at this point is not in fact their own (2008, pp. 74-75).

The idea of choice is further complicated for Mol because the facts — on which care decisions are based — are not factual, but rather intertwined with values (2008, p. 74). Consequently, she contends that informing a patient that they have a particular pathology is an interactive and negotiated process that is inherently imbued with values. Accordingly, for Mol, the process of disclosure of a pathology is a negotiation between healthcare provider and patient (2008, pp. 11, 18, 20). Furthermore, she writes that within the case of diabetes, the fact that there are no facts has to do with the complications and the complexities of the disease itself (2008, p. 45), meaning that the idea that there is something called a “normal blood sugar level” and then conversely an abnormal one is not a *fact*; rather, she suggests, it is much more complex (2008, pp. 45-46). This assertion enables me to consider the circumstances through which *truths* about HIV and pregnancy are produced and negotiated

within the power relations of the antenatal clinic. For example, the presence of HIV during pregnancy may entirely alter accepted truths about gestational health. Therefore, it can be seen that the common sense knowledge that it is potentially detrimental to take toxic drugs while pregnant changes if the pregnant woman is HIV-positive and it becomes a statement where *toxic drugs are vital to the future baby's health*. These *truths* are not necessarily easy to assimilate into practice.

In this way, the choice that Mol was given by the nurse regarding whether or not she was to have an amniocentesis could not be provided in the specialist antenatal clinic if the procedure was considered by the practitioners to be potentially detrimental to the patient's future health or the future health of her unborn baby. For example, in relation to care in the specialist clinic, the option of not taking ART during pregnancy is not presented to HIV-positive pregnant patients as a viable choice for them.<sup>48</sup> Of course, this does not mean that the patient is not able to choose to refrain from taking ART. Rather, I suggest that this choice would not be accepted or respected by the practitioners as if it were made by a fully autonomous individual who was capable of making informed decisions about her care.<sup>49</sup> Importantly, I am not suggesting that the practitioners would force a patient to take ART, rather, my intention is to make clear that a patient's choice *not* to take ART would not end the practitioners' efforts to convince her to take them.

Following this, choice as a viable activity that the patient is encouraged to engage in has its limits — or rather, I argue it ceases to exist after the patient has *chosen* to be a patient in the specialist antenatal clinic, if and when she behaves in a way that is considered to be detrimental to her health and/or the health of her unborn baby. In other words, after her formal induction into the clinic, the assumption is that the patient has acquiesced to participate in a process that will provide her and her unborn baby with the best possible care,

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<sup>48</sup> Another example: pregnant HIV-positive women are not offered the choice of having a home birth or a hospital birth. This is because a home birth is considered to be too risky and not conducive to the requirements of the prevention of vertical transmission.

<sup>49</sup> It must be mentioned that Mol contends that within a "logic of choice", the patient's ability to choose functions in the same way. In other words, there is no *real* choice as such.

ensuring the prevention of vertical transmission and optimal outcome for their health. Participating in this process requires a certain kind of behaviour on her part, the particulars of which are constantly up for negotiation, but ultimately it is the practitioners that determine what that behaviour ought to be. Therefore, the practitioners have carefully assessed the potential consequences of any choice that is presented to the patients in the clinic to ensure that the potential effects of those choices would not impede the practitioners' ultimate goal.

Returning to Mol's logics, she argues that within the logic of care there is only a single normative layer and that "the crucial moral act is not making value judgements, but engaging in practical activities" (2008, p. 75). Accordingly, within the logic of care, "doing good" is good, and making life "better" is desirable (2008, p. 75). However, Mol importantly contends that the particularities and meaning of [doing] "good", "better" and "worse" and what constitutes and enables a "better life", are not predetermined, prior to enactment and/or practice; rather, they "form part of [practice]" (2008, pp. 75-76). Making decisions about what constitutes a better life is, Mol suggests, a collective decision, established through negotiations with the relevant actors in all its complexity (2008, p. 76).

It is here that I would like to further Mol's argument by contending that the relevant actors that take part in the negotiations mentioned above include the practitioners' imagined future patients — both the mother as she will be postnatally, if vertical transmission is prevented and she has a *healthy* baby, and the baby born free of HIV. These are the ideal patients that are kept in mind when dealing with resistant (and sometimes hostile) pregnant patients. As mentioned above, the fact that the pregnant patient has chosen to continue with her pregnancy illustrates that her future self (as the practitioners imagine her to be if vertical transmission is prevented) would be glad that she participated in a process that ensured the prevention of vertical transmission. In other words, the patient that is consulted about care choices is not limited to the present time patient.

Mol advocates the need to reposition “choice” as a “defining face of human life” (2008, p. 73) to one wherein it will be viewed simply as an “activity” that may or may not be good to engage in, depending on the particularities of the situation within which it arose (2008, p. 73). Following this move, she argues site-specific questions would need to be posed such as “where and when to organise situations of choice where and when other configurations might be more appropriate” (2008, p. 73).

Mol’s arguments are valuable when addressing concerns related to the particularities of the space of the antenatal clinic: for instance, what are the factors that would dictate the type of configurations into which bodies would be organised within the antenatal clinic? However, her argument is less useful when trying to approach or make sense of things that are not articulated in the clinic prior to becoming enacted in practice. In other words, Mol’s assertions do not elucidate the extent to which the configurations apparent in the antenatal clinic may be (or are) affected by forces and/or variables that remain unarticulated.

To conclude this session, Mol’s propositions are useful when considering the intricacies inherent in both pregnancy and HIV. In this regard I suggest that her thesis allows for an investigation into the complexities of pathologies and certain conditions, and the medicalisation of bodies, as they appear within the clinic. In other words, Mol’s arguments are useful to the investigation of circumstances that are enacted in the clinic and the logics of care that inform care practices in the clinic. However, the practitioners’ focus on the wellbeing of the future patient and her hopefully HIV-negative baby changes the idea of the present-time patient’s autonomy in relation to her ability to make decisions or to be offered choices in regards to her care.

## Conclusion

The ability to successfully prevent vertical transmission of HIV in resource rich locations is an unquestionable achievement. However, this chapter has clarified that while the problem of HIV in relation to vertical transmission can be resolved in the clinic through the use of biomedical technologies and care, the problem of HIV is not limited to the transference of the virus between mother and baby. Thus, this chapter has outlined theoretical insights that I will use in the subsequent chapters in order to further explore the contingencies of HIV in the clinic.

Based on the literatures discussed in this chapter, I have taken the idea that within the space of the HIV specialist antenatal clinic, different kinds of issues emerge from the practices that are connected to, amongst other things, different locales, technologies and understandings of HIV. It is in relation to these concerns that Fassin is useful in that he emphasises the importance of investigating how traces of these geopolitical dynamics are articulated and negotiated in the clinic. However, these issues extend to other aspects of the clinic such as the technologies that it depends on, and it is here that the work of Annemarie Mol is of particular assistance. Consequently, by using Mol I argue that the technologies used in the clinic participate in the construction of certain kinds of *HIVs* as well. Moreover, these problems follow the patients into the clinic and trickle through every aspect of the events that take place within it. In response to this, later chapters will question the way bodies are identified as belonging to geographical locations that are imbued with significance, regardless of the current location of the bodies in question.

At the onset of this thesis, I contend that the space of the antenatal clinic is the subject of analysis. Following this, it is clear that I will explore a space which encompasses domains, which are simultaneously social, and biomedical. My position is that what HIV is (discovered to be) within the clinic and the areas that the patients and practitioners within in it negotiate, will depend entirely on who or what is *asked* to provide an account of HIV. Moreover, all of the accounts provided will have been filtered, and in this way,

they do not represent a comprehensive account of the problem of HIV. Further to these ideas, the next chapter will discuss the methods used to conduct this study and consider the experience of conducting research in a highly emotive environment.

### **Chapter Three: Methodological Negotiations and Emotive Perspectives**

This chapter will outline the methodological issues which were explored in order to conduct this study. The project devises a research methodology attentive to practices drawn from science and technology studies (STS). Therefore, the discussion will be positioned within debates prevalent in some versions of STS that consider the enactment of disease and provision of care, as well as social scientific and anthropological discussions that reflect upon the significance of intimacy and the experience of doing research. Moreover, the chapter will consider the decisions made in regards to choosing research participants, along with the process of collecting and analysing data. Furthermore, the chapter will reflect upon some of the ethical constraints and shortcomings of the study.

#### **Uncovering the specificities of HIV and pregnancy through practice**

In “Embodied Action, Enacted Bodies: the Example of Hypoglycaemia” (2004), Mol and Law argue the idea that diseases, in particular hypoglycaemia, are enacted in practice, as is the body (affected by disease). In this article, they explore the practices that take part in the enactment of a disease in order to investigate the question of “what is a body” (Mol and Law, 2004, pp. 43, 45). In other words, they use ethnographic methods to describe how bodies and diseases are done through practice. They state: “[as] part of our daily practices, we also do (our) bodies. In practice we enact them” (2004, p. 45). Following this, Mol and Law provide an ethnographic description of hypoglycaemia (2004, pp. 46, 49) through their investigations of clinical presentations, trials and epidemiological overviews (2004, pp. 46, 49) and by asking people with hypoglycaemia what it is, how they attempt to “intervene into it”, “counter act it”, avoid it and attempt “not to know it” (2004, p. 49).

Mol and Law speak to health care providers about hypoglycaemia (2004, p. 47) and in this way get a feel for how practitioners see this condition, as well as what is required of their patients in addition to an “appropriate

engagement” with relevant technologies (2004, p. 47). Thus, they report that a nurse speaks about the significance of a patient’s “self-awareness”; patients who are self-aware are, according to this professional, able to live more “flexible lives” (2004, p. 47). Moreover, they observe hypoglycaemia where it is “beneath the skin”, located within text books — where it is situated as a consequence of various “treatment practices” and is thus found

in hospitals, information leaflets and people’s homes. It is in the daily lives of people who suffer from diabetes mellitus. In daily life hypoglycaemia is something that may occur, happen, be done (Mol and Law, 2004, p. 46).

Consequently, they received a multitude of answers from various respondents to their question of “what is hypoglycaemia” (2004, p. 50)? Their next question was what the answers implied “for the body” (2004, p. 50). In response to this question they write

The answer is, two things. First, as they enact hypoglycaemia, bodies *do* a lot of things: they *act*. And second, while it is measuring, feeling, countering, avoiding and producing hypoglycaemia the body is *being enacted*, too. But no, it is more complicated still. For acting and being enacted go together. Thus we may ask: while it is acting, what is a body made to be (2004, p. 50)? (Emphasis in original)

In order to answer this question, they use stories from the lives of people affected by the disease to illustrate what acting and enacting do. Accordingly, they explore the way the technologies that patients are meant to use interact with their lives, and the way in which people are required to reorganise their lives in order to fit into the requirements of the technology. To illustrate their point, Mol and Law provide details of the difficulties affected people thus face as a result of other obligations that they have. For example, they describe how a manual labourer finds it difficult to prick his finger to test his blood during his workday because he cannot access clean water to wash his hands (2004, p. 50).

From this they discuss the way some of the technologies people are required to engage with attempt or encourage them “to stop whatever they are doing in order to feel their bodies from inside”, thus “[training] inner sensitivity” (2004, p. 48). Importantly, Mol and Law also consider how various methods of caring for people with hypoglycaemia may have different ways of enacting the body of the person with the disease, as well as different effects on the patient’s life, and the way she lives her life (2004, p. 55). The next section will reflect on another text by Mol that is explicitly concerned with the logics of care.

### **Finding good care**

In *The Logic of Care*, Mol analyses the practices involved in living with and treating diabetes which promote “good care” (2008). Mol is able to speak about this concept because her methodological approach enabled her to establish what “good care” is in practice. In other words, the methods that Mol used to conduct her study, as well as the way she treated the data she collected, allowed her to uncover it. Hence, Mol writes that she worked with her empirical material similar to the way a chemist handles “mixed liquids”, since a chemist would “distil it in order to separate out” various components (2008, p. 10).

Accordingly, Mol spent time in clinics collecting data in numerous ways to observe care practices. The materials that she thus distils have been gathered in different ways from multiple sources (2008, pp. 8-9). In other words, she sifted through her data in order to establish what “good care” is. Her intention was to amass “snapshot stories about the treatment of, and life with, diabetes inside and outside of the hospital” (2008, p. 2). Fieldwork was conducted in an ethnographic mode; she attended patient consultations, and analysed lay and professional texts on diabetes in books, journals and websites. Furthermore, she conducted interviews with practitioners and patients.

For Mol, fieldwork is necessary in order to articulate the logics that she argues are embedded within practices (2008, p. 8). This is because the rationality of the practices she is interested in, i.e. the logic of these practices, may be “[implicitly]: embedded in practices, habits and machines” (2008, p. 8). Moreover, the logic of these practices may not be “obvious to the people involved” in the practices or even “verbally available to them” (2008, p. 8). Consequently, according to Mol, it is only through the process of immersing oneself in the field and observing practice that the researcher is able fully to appreciate the logic(s) that determine the way in which practice is enacted within a particular environment. Furthermore, her approach embraces the idea that the final product, as she presents it, is intentionally selective. This is significant to this study as will be discussed later in this chapter.

Influenced by Mol and Law, I am interested in investigating the practices that take place in the enactment of both HIV and pregnancy in the clinic. In a similar way, this exploration helped me understand what a body is in the clinic (Mol and Law, 2004, pp. 43, 45). Thus, like Mol and Law, I use ethnographic methods to describe how HIV-positive pregnant and postnatal bodies are done through practice (2004, p. 45).

More specifically, Mol and Law’s approach persuaded me to ask the practitioners in the clinic about what they felt HIV and pregnancy were for them and for their patients, and what they felt an “appropriate engagement” with relevant technologies was for their patients in order to prevent vertical transmission of HIV (Mol and Law, 2004, p. 47). Furthermore, Mol and Law’s approach encouraged me to observe HIV and pregnancy as they were situated as a consequence of various “treatment practices” (2004, p. 46). Moreover, I took from them the idea that various methods of caring for HIV-positive pregnant women could have different ways of enacting the HIV-positive woman’s body and her (unborn) baby’s body, and thus also have different effects on both of their lives (2004, p. 55).

The methodological contribution that *The Logic of Care* (2008) makes to this thesis concerns the way Mol conducted her fieldwork and treated the data she collected. Thus, from Mol I take the methods she used in order to separate

out “good care” from “messy practices” (Mol, 2008, p. 10). While many of Mol’s and Law’s arguments are directly relevant to this study, our thinking departs from each other in a few ways, which I will discuss below.

### **Intervening into both HIV and pregnancy**

The idea of intervening into a disease and/or counteracting it, and attempting to know or not know a disease, are particularly interesting in relation to HIV and pregnancy. This is especially considering that many women may enact a combination of these responses. An extreme example of this could be HIV-positive pregnant women who may not want *to know* HIV but yet still have a healthy pregnancy, or who may want to *counteract* HIV but not in any way *intervene into* their pregnancy. Here it is important to consider that many HIV-positive people do not experience significant symptoms of their HIV prior to taking ARVs, which can have serious and sustained unwanted effects (Rosengarten, 2009, p. 4). Therefore, in relation to HIV, in some circumstances it may be more appropriate to describe the patient’s desire to intervene into the disease as being a desire to intervene into the “unwanted effects” of the medication she is taking.

Furthermore, the concept of inner sensitivity (Mol and Law, 2004, p. 48) discussed above is noteworthy in relation to the HIV specialist clinic when considering the fact that it is both HIV and pregnancy that are being cared for in the clinic. As mentioned elsewhere in this thesis, certain symptoms such as vomiting could be considered normal symptoms of a healthy pregnancy, or they could allude to the possibility that a patient may be experiencing unwanted effects of ARVs. Accordingly, the implications of inner sensitivity may vary drastically depending on what a patient and/or practitioner decides is the cause of the patient’s symptoms. Later in the thesis, I will show that these contradictory positions may have substantial implications for care.

Likewise, Mol’s ethnographic method and her preoccupation with practice do not specifically encourage consideration of the feelings and thoughts of researchers. Nor does her approach prompt a focus on the emotive

relationships that may develop between researcher and research participants. However, on entering the field it became abundantly clear to me that my thoughts and feelings about the research process and the research participants significantly influenced the way I conducted myself in the clinic, and how I made decisions about how to write about the clinic. Therefore, I found the work of Clifford Geertz (2001), Julia O'Connell-Davidson (2008), and Fraser and Puwar's discussion of O'Connell-Davidson's work particularly useful when trying to make sense of the intimacy that arose between the research participants and myself and the experience of conducting research in a clinic with vulnerable patients. A description of their contribution will be discussed below in relation to analysing and disseminating research and the emotive experience of being in the field.

### **The experience of doing research**

In "Thinking as a Moral Act: Ethical Dimensions of Anthropological Fieldwork in the New States", Clifford Geertz argues that the significance of the social sciences is that their theories and methods are derived from the social world, thus they are produced by the people who live in the same social worlds to which these "methods apply and theories pertain" (2001, p. 22). Following this, Geertz argues that thinking (about the social worlds the researcher inhabits) is a social act (2001, p. 21). In other words, for Geertz, "thought is conduct and is to be morally judged as such" (2001, p. 21). This argument, he writes, brings "thinking out into the public world where ethical judgement can get at it" (2001, p. 21).

Geertz contends that "the moral quality of the experience of working social scientists, the ethical life they lead while pursuing their inquiries [...] should be a central aspect of modern consciousness" (2001, p. 22). To use Mol's vernacular to stress this point, Geertz would argue that thinking is enacted in practice. However, as I touched upon in the previous chapter, thoughts and feelings only become *heard* if they are articulated in some way. So, thinking is a moral act that is intrinsically connected to the lived experience of being in

and becoming with the field. However, despite the relevance of these processes, Geertz contends that “the moral quality of the experience of working social scientists, the ethical life they lead while pursuing their inquiries, is virtually never discussed except in the most general terms” (2001, p. 22). These arguments resonate with me, and so, like Geertz, I will discuss some of the ethical dimensions of my time in the clinic in an attempt to offer up my thought processes for ethical judgement.

As mentioned above, the emotive experience of being in the clinic became increasingly important to me while I was conducting fieldwork. Furthermore, my feelings have intensified since leaving the clinic through the process of further analysing the collected data and writing it up. In a similar way, O’Connell Davidson reflects upon the relationship she developed with a research subject in her article, “If no means no, does yes mean yes? Consenting to research intimacies” (2008). Here O’Connell Davidson asks whether or not the intimacy that may arise between a researcher and her research subjects is ethical just because the researcher has obtained informed consent from the research participant (2008, p. 49). Further to this, and because of the kind of relationship she developed and eventually lost with her research participant “Desiree”, O’Connell Davidson questions the extent to which it is possible for a research participant to fully “consent to being objectified through the research process” (2008, pp. 50-51). What I take from O’Connell Davidson’s article is the significance of the relationship she established with her research participant to the production of data. In response, I will consider how my relationships to my research participants influenced the empirical material I collected. Moreover, I will discuss how O’Connell Davidson’s decisions about what she finally chose to write about in regards to Desiree (and what she omitted from dissemination) impacted upon the way I decided not to include certain themes in this thesis.

In “Introduction: Intimacy in Research”, Mariam Fraser and Nirmal Puwar consider O’Connell Davidson’s article and the manner in which intimacy is produced during the process of doing research (2008, p. 1). Fraser and Puwar contend that despite the fact that “sensory, emotional and affective relations”

are an integral part of the research process, they are often made to be invisible and are not adequately considered in discussions about methods and methodology, or in researchers' discussions of the experience of doing research (2008, p. 1). They argue that the reasons for this invisibility has to do with (amongst other things) the generally accepted standards of academic practice and the way in which researchers grapple with "relations between scholarly research and personal relationships across time, and between scholarly research and, for example, creativity, fiction, or sensationalism" (2008, p. 1). The invisibility of the affective dimensions of the process of doing research is particularly problematic, they contend, because intimacy informs the production of knowledge, power relations and the way researchers grapple with ethical problems (2008, p. 1). In other words, by not directly attending to the affective dimensions of their research, researchers are neglecting to discuss issues that are fundamental to all aspects of their work.

Moreover, they argue that researchers generally wish to describe their research methods as if they are distinct from their emotions (2008, p. 4). Following this, Fraser and Puwar write that the researchers' experience in the field as an "embodied being" is consequently absent from academic discourse (2008, pp. 9-10). However, they argue that trying to fill in these absences brings forth new concerns — which are exemplified in O'Connell Davidson's article — in that the boundaries between the role of researcher and friend or confidant are blurred during the process of data collection and dissemination (2008, pp. 9-10). Therefore, Fraser and Puwar write that a consequence of the intimacy established between researcher and her research subjects may be that "[the] dissemination of primary data to a wider public can be plagued by a sense of betrayal and disloyalty" (2008, p. 10). Taking my feelings of unease at the prospect of disseminating this research seriously, I have chosen to provide details of my emotive response to being in the clinic, to the people that I met in the clinic, and to the way in which our relationships developed.<sup>50</sup>

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<sup>50</sup> Treating my emotions in this way reflects Reger's (2001) position in "Emotions, Objectivity and Voice: An Analysis of a 'Failed' Participant Observation", in which she argues that researchers must treat their emotions as data.

## **Description of method**

Moreover, this study's methodology was influenced by grounded theory (Glaser and Strauss, 1968; Corbin and, Strauss 1990; Charmaz, 1990; 2006; 2008a; 2008b; Glaser and Holton, 2004; Mason, 1996). I was attracted to the openness of grounded theory; it did not appear to have unnecessarily strict boundaries but was instead open to be augmented. As Charmaz writes in regard to this, "[g]rounded theory has evolved into a constellation of methods rather than an orthodox unitary approach" (Charmaz, 2008a, p. 161) (see Glaser and Holton, 2004, paragraph 7). I was drawn to the way in which grounded theory requests that a researcher asks questions about what is happening in the field and "[w]hat (theoretical category or theory) are these data a study of" (Charmaz, 2008a, p. 161). Additionally, this approach appealed to me because I did not want to enter the clinic with a pre-existing checklist of phenomena to be observed (Charmaz, 1990, p. 1162). Instead, I wanted theoretical categories to emerge from and be grounded in the data (Charmaz, 1990, p. 1162; 2007, p. 82; a2008, p. 163). In this way, Mason writes that grounded theorising is an instance where both theory, as well as explanation, comes from the emerging analysis that is enabled through "constant comparative methods" (1996, p. 142). Grounded theory encouraged me to closely examine the clinic, to evaluate what emerged in the clinic, and to connect the empirical world I was part of "to theoretical possibilities" (Charmaz., 2008a, p. 161).

However, I did have concerns with grounded theory. My reservations about this approach had to do with what it purports to tell us about the worlds studied. Charmaz has argued that "by starting with data from the lived experience of the research participants, the researcher can, from the beginning, attend to how they construct their worlds" (1990, p. 1162). Nevertheless, I was (and am) part of the worlds that I research (Horsburgh, 2003, p. 308). Therefore, I am a part of all aspects of this study: the data

collected from the research participants as it concerns their lived experience and the way in which I imagine that they construct their worlds. Thus, while the participants of this study lived a reality without me, I was not able to access that reality without making myself part of it. Instead, I am suggesting that my approach is indicative of a less sharply distinguished relation between researcher and her research object or participant. In this way, my concerns with the approach advocated by grounded theory have to do with claims about what the process may tell us about the world. I do not have concerns about the process itself. In other words, the tools grounded theory provides are good tools, so I used them. The next section will describe how I gained access to the clinic.

### **Approaching the clinic**

When I conceived of this research project, I had two hospitals in mind as possible sites to conduct my study. Out of all the London hospitals, two had the busiest HIV specialist antenatal care facilities. I emailed HIV specialist practitioners in both places and quickly received courteous responses. However, my contact at the first hospital assured me that *his* clinic did not care for a significant number of HIV-positive pregnant women. He suggested that the London Hospital would be a better site for me. Moreover, “Anne”,<sup>51</sup> an HIV specialist consultant physician and my contact at the London Hospital, was very enthusiastic about my project and her clinic cared for more HIV-positive pregnant women than any other hospital in London. Prior to gaining ethical approval from the NHS, I visited the hospital on many occasions in order to meet with various practitioners to discuss my research.<sup>52</sup> The first visit to the hospital took place in November 2007.

Influenced by Mol’s approach to ethnography, I commenced fieldwork in the clinic with an interest in discovering and understanding what was happening

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<sup>51</sup> All of the participants have been assigned pseudonyms. A more detailed description of my relationship with Anne will follow.

<sup>52</sup> I will expand upon my initial experiences with the clinic and practitioners later in this chapter.

there. Similar to Mol, a number of different data-gathering techniques were employed for this study in order to observe practice and care in the clinic: participant observations, unstructured in-depth qualitative interviews, and informal conversations. While the methods I used to conduct this study are undoubtedly ethnographic, I did not adhere to the approach taken by a more traditional anthropological ethnography. Thus, I did not observe the daily lives of my informants for an extended period of time (Hammersely and Atkinson, 1995, p. 1; Walsh, 2004, p. 226). Nor, like what Fassin states in reference to his ethnographic work, did I assume that it was possible for me to provide an all-inclusive description of my informants or the clinic (2007, p. xxi). Instead, and in line with the way Charmaz has defined ethnography, my approach was oriented towards remaining open to the events that took place in the clinic and to the people that frequented it (2006, p. 21).

Therefore, upon entering the field my initial question was “what is going on here”? I often felt silly when asking basic questions like this but they were essential for forming a better understanding of the events that occurred in the clinic, rather than relying only on observation (Charmaz, 2006, p. 22). A follow-on question I asked was “what is ‘here’”? In other words, what is this space I am trying to investigate? Who are the participants in this space? Where have they come from and how do they negotiate the space and their inclusion into it? Are the events that take place “here” confined to this space (whatever it is)?<sup>53</sup>

Consequently, the organisation of the specialist clinic, both physically and logistically, was of interest to me. Where are the patient’s medical notes stored and moved around within the hospital? What happens in the consultation rooms, waiting room and other spaces in the clinic? Who is in charge of these spaces, if anyone? How do the HIV specialist clinic’s patients’ interact with patients and care-providers and administrators from other clinics? How do the HIV specialist care providers interact with other medics

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<sup>53</sup> These questions were prompted by the structure of the clinic and the temporary nature of the space. Further to this, the question of what “here” was more complicated to explore because while the clinic sessions took place once a week, the care that was provided by the practitioners was not limited to the session. For example, the HIV specialist midwife would keep in contact and meet with patients outside of the clinic sessions.

and administrative staff? As I will expand upon later, these questions helped me develop further questions and eventually theoretical categories that then assisted me in directing subsequent data collection and analysis (Charmaz, 2006, p. 25).

Further to this, I was particularly interested in tracing HIV, pregnancy, (unborn) babies, patients, and technologies used in the management of HIV. As I began to spend more time in the clinic, collecting and analysing data,<sup>54</sup> my list expanded to include “good” (becoming) mothers, resistance and compliance to care, the patients’ religion and family. Moreover, I was attuned to the way in which the practitioners and patients connected to the clinic did (or did not do) “HIV”, “pregnancy” and “HIV-positive pregnant bodies”. For example, attention was paid to the way HIV (positivity), pregnancy, and maternity were spoken (or not spoken) about, (apparently) understood, approached and discussed by the research participants, as well as the expectations they had of themselves and each other, and how these were expressed, fulfilled or left unsatisfied. Likewise, the way in which relationships between participants developed and were maintained, negotiated and severed was of interest to me. Hence, I was especially attentive to the research participant’s opinions of the clinic, as well as to each other and to the people connected to them. My ethnographic approach has retained Mol’s interest in discovering what a body is (within a specific environment), how disease is done there, and what the logics of care are that enable and promote “good care” within that space.

### **Ethical approval**

Ethical approval to conduct this study was granted by the NHS Research Ethics Committee (REC), the Research and Development office (R&D) at the London Hospital, as well as the Research Ethics Committee (REC) at Goldsmiths, University of London. The process of gaining ethical approval from the NHS REC is lengthy and complex and initially involves filling out an

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<sup>54</sup> A more detailed description of how data was collected and analysed will follow.

online form with questions that are meant to assess the ethicality of the proposed project. Once the form is complete, the applicant submits it and thus begins a multifaceted journey, the intention of which is finally to gain clearance to commence fieldwork.

While the entire process of gaining ethical approval from the NHS REC could very well be the subject of a thesis in its own right, I will only provide a flowchart in an appendix to this thesis detailing some of the steps that were taken in order to gain approval. Not mentioned in the flow chart, however, are all of the additional requirements that may or may not be necessary, depending on the researcher. For example, I was asked to redo many of my childhood vaccinations,<sup>55</sup> as I could not produce medical records that confirmed that I had had them, and my childhood was spent abroad.

In contrast, the process of gaining ethical approval from Goldsmiths was straightforward. I met with the head of the Goldsmiths REC, although this was not a part of the requirement to gain approval. We had an enjoyable informal chat about research ethics. After this, I filled out a short form and submitted it via email to the REC. Shortly thereafter, I received notice that my project had been approved.

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<sup>55</sup> In fact, the vaccinations were a requirement of the London Hospitals' "honorary contract", which was needed in order to fulfill the requirements of the Research and Development office at the London Hospital.

## Consenting processes and gatekeeping

As mentioned above, my initial access to the clinic was negotiated with the help of Anne, one of the clinic's consultant physicians. Thus, Anne was the initial gatekeeper (Walsh, 2004, p. 229). Anne and I had extensive discussions about how my project should be introduced to both patients and practitioners. In accordance to the way I described the procedure in my NHS REC application, Anne dictated that practitioners would be in charge of informing patients about the project, recruiting patients for interviews and seeking verbal consent to have me attend consultations. Moreover, I would be responsible for seeking verbal consent from members of the MDT to attend meetings and otherwise spend time with them. The procedures for gaining verbal consent, outlined above are in accordance with Ali and Kelly's advice for contending with situations where it would be difficult to gain informed written consent (Ali and Kelly, 2004, p. 121). It would have been very challenging indeed to ask and expect each and every participant in the various MDT meetings to delay the meeting so that they could all sign a consent form. Moreover, before gaining approval to commence the project Anne requested that I meet with several senior and/or influential members of the MDT to gain their support.<sup>56</sup> Further to this, Anne invited me to an MDT meeting so that I could inform the team about my project and request their participation.

After receiving approval from the hospital's R&D department to commence the project, Anne introduced me to Sophia, an HIV specialist doctor who was preparing to take over the clinic from the clinics' previous HIV doctor.<sup>57</sup> After this, Anne left the hospital for a six-month long research leave. Thus, Sophia took on the responsibility of informing patients about my project and recruiting patient participants. Ellen also helped me establish connections to other members of the MDT. For example Laura, an HIV paediatric nurse, told me

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<sup>56</sup> I will not expand upon these meetings or explain who they were with. This is because they took place prior to me having received R&D approval to commence the study.

<sup>57</sup> Consultant physicians and HIV doctors would normally be placed in the clinic for a six-month period, although Sophia stayed longer than this. I will not expand upon the reasons for her extended stay.

that she had only agreed to be interviewed after Ellen had made it clear that she approved of me.

Ellen and Sophia were responsible for informing patients about my project and they always negotiated with the patient and received their initial verbal consent to participate. I never witnessed these exchanges. However, Sophia told me that she would normally give verbal information to patients about the project while making the written information available. Then, during their next visit to the clinic, Sophia or Ellen would ask the patient if I could observe their consultation. The patients gave Sophia or Ellen verbal consent to allow me to observe each and every consultation that I attended.<sup>58</sup> As a point of contrast, Mol describes the way in which a practitioner sought out patient consent to participate in her study:

The surgeon walks to the door and calls in the next patient. They shake hands. The doctor points at my presence and says that I'm there to learn something. He sits on a chair behind his desk. The patient, a woman in her eighties, takes a chair at the other side of the desk, clutching her handbag on her lap (Mol, 2002, p. 21).

Mol continues to provide a verbatim rendition of the consultation (2002, p. 21). It is worthwhile to mention that it is of course possible that the patient had received more information about the study, but if this were true, Mol does not write about it. What Mol's case makes clear is that the onus of informing a patient about a project lay with the patient's healthcare provider. In my situation, I did not feel that I was in a position where I could dictate to the health care professionals how I wanted them to negotiate consent, or inform patients of my project.

Returning to my study, Sophia asked some of the women who had consented to let me observe their consultations if I could interview them. If they agreed she would give them my contact information. Sophia and I decided that she

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<sup>58</sup> According to Ali and Kelly (2004), giving verbal information to potential research participants about a study is in accordance with the parameters for ethical research practice provided by the Declaration of Helsinki.

would only approach patients for interviews if Sophia deemed them to be relatively low risk patients — meaning that the patients were known to adhere to their medical treatment and that they were not currently experiencing acute social issues.

Thus, during each clinic session I asked one of the members of the MDT who met with patients (Sophia, Ellen or Marie) if I could attend their consultations. Verbal consent was given,<sup>59</sup> after which the practitioners would negotiate consent for me to attend consultations from their patients, as described above. Research participants were only asked to sign a consent form if and when they had agreed to be interviewed by me. The way in which potential research participants were informed of the project and the way in which consent to participate was negotiated was in accordance with the description of the process that I provided in my NHS REC form.

### **Participant observation in the clinic**

After meeting all of the requirements to conduct this project,<sup>60</sup> I ended up spending nine months in the clinic doing fieldwork, from July 2008 until March 2009. During this time I attended twenty-nine specialist antenatal clinic sessions, which were all of the sessions held during this period, and I observed consultations held by all of the health practitioners who saw the clinic's patients during my time there.<sup>61</sup>

All in all, I regularly attended the consultations of twenty-one different patients.<sup>62</sup> A total of forty-eight different women were discussed by the practitioners, thirty of these women attended appointments at the clinic while I was there, and the rest were either anticipated patients, or former patients.

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<sup>59</sup> None of the practitioners ever denied my request.

<sup>60</sup> These requirements concern the process of gaining ethical approval to conduct a research project within the NHS.

<sup>61</sup> Sophia, Ellen and Marie.

<sup>62</sup> Of these 21 women, I had to sit in the waiting room during one of Eleanor's consultations because Sophia and Ellen were on high alert for an extremely volatile patient (Field Notes, 27 August, 2008).

For example, Patient Number 47”<sup>63</sup> who miscarried before Ellen was able to register her as a patient, or Patient Number 28”, who was pregnant but not HIV-positive; however, she was in contact with the clinic because her husband (a patient at DOSH), was HIV-positive, and they had told the MDT that using condoms compromised their religious beliefs. Connected to each of these women were their families, who were also discussed and who occasionally attended consultations.

Out of these thirty patients, four were born in the UK and were mixed race (either white British and Black Caribbean, or white British and Black African), while the rest of the women were Black African and from countries in Sub-Saharan Africa.<sup>64</sup> The clinic’s patients’ ages ranged from their early twenties to mid-thirties, with most of them being in their twenties.<sup>65</sup> A French interpreter attended one of the patients during a consultation — otherwise all of the consultations were conducted in English — although many of the women whose consultations I attended apparently had only a perfunctory grasp of the language. Moreover, many of the patients in the clinic were either illiterate or had limited reading and writing abilities.

There were nine patients whose consultations I never sat in on, although I would nonetheless hear about these women during the practitioners’ meetings. Of these women, six were never asked if I could meet them. They were, for various reasons, deemed by the practitioners to be too volatile and/or had already expressed a dislike for being introduced to new practitioners. For example, Patient Number 1” told Sophia that she was reluctant to speak to people about HIV. Consequently, the practitioners would try and avoid introducing her to new people. The three remaining women who

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<sup>63</sup> Later in this chapter, I explain the way in which I “named” research participants and the people they spoke to me about.

<sup>64</sup> One of the women that I interviewed was from the Caribbean; however, she was not a patient in the clinic during my fieldwork.

<sup>65</sup> Theodora was nineteen when she first became a patient; she had a birthday during her time in the clinic.

had been asked if I could sit in on their consultations declined, also for diverse reasons.<sup>66</sup>

The data for this study was collected in numerous locations: consultations between patients and practitioners (Sophia, Marie and Ellen), informal chats between the practitioners and myself, MDT meetings, interviews with patients in the antenatal clinic, and at the DOSH. Additionally, I helped out at a community outreach session organised by Sophia on behalf of DOSH, interviewed practitioners in the antenatal clinic, at the DOSH and in the midwives' offices and at two other London hospitals where I interviewed two other members of the MDT,<sup>67</sup> and at the homes of several patients.<sup>68</sup> Moreover, I spent time at the paediatric ward at the London Hospital where I met another member of the MDT but did not interview her, and at the maternity ward visiting postnatal patients and their babies. I accompanied patients to the "blood clinic" to have their blood drawn, and spent time with patients in other areas of the hospital.

## **Interviews**

Five health practitioners were interviewed for this project: Ellen, the HIV specialist midwife, Sophia, an HIV specialist doctor, Anne, a consultant physician, Laura, a HIV specialist paediatric nurse and Leslie, an HIV specialist community nurse. Second interviews were held with Ellen and Sophia. As mentioned previously, Ellen was the only health professional in the clinic that cared exclusively for the clinic's patients. Three of the practitioners interviewed were white British, while Sophia and Laura were black women of African descent, one UK born, and one from South Africa. The interviews lasted for about one hour. All of the interviews were recorded with a Dictaphone with the interviewee's consent and later transcribed by me.

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<sup>66</sup> Patient Number 25" said "no" without giving Sophia a reason. Patient Number 14" said no because she was contending with her husband's infidelity.

<sup>67</sup> An HIV specialist community nurse and an HIV specialist pediatric nurse. Both nurses were members of the MDT but they were based at other London hospitals.

<sup>68</sup> I visited Celine, Elisabeth and Eleanor.

While the number of health practitioners who regularly interacted with the clinic's patients in the clinic was very small (Ellen and Sophia), seventy-five professionals overall were either discussed and/or present in the hospital, or in some way connected to the patients and/or MDT during my time there. These professionals include support staff within the NHS, such as members of the hospital's legal team, employees at various NGOs, and social workers and health professionals at other NHS trusts.

During the course of this project, I interviewed nine patients, and held second interviews with three of them, as well as a third interview with one woman. All of the patients interviewed received a small monetary compensation for their time and expenses. The first interviews with patients took place in a consultation room in the antenatal clinic, and the second interviews took place in a consultation room in the DOSH — except for four interviews with three women which took place in their homes at their request. Interviews conducted at the hospital lasted about an hour as I was not able to secure rooms for longer periods. The interviews held at patients' homes lasted between 2-3 hours.<sup>69</sup> The increased length of time was always at the patient's initiative. All of the interviews were recorded onto a Dictaphone and transcribed by me. The patients were given the participant information sheet and consent form, which I read aloud.<sup>70</sup>

Two patients declined to be interviewed when asked by Sophia. One of the women did not offer her reasons and the other said that her husband would not let her (Field Notes, 17 December, 2008, p. 5; 18 February, 2009, p. 10). He was worried that taking part would be too upsetting for her (Field Notes, 17 December, 2008, p. 5). Another patient, Patient Number 31", agreed to an interview but I was not able to schedule an appointment with her (Field Notes, 11 February, 2009, p. 7). Finally, one other woman agreed to be interviewed but I ended our meeting before she signed a consent form.

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<sup>69</sup> The last interview with a former patient took place in May 2009.

<sup>70</sup> The practitioners were given the same forms but I did not offer to read them aloud.

All of the women whom I interviewed (and were asked if they would be interested in being interviewed) had come to know me several weeks before the interviews took place — exceptions were Evelina and Theodora. Evelina was a postnatal patient whom Sophia thought would be an excellent person for me to interview because of her talkative nature and compelling background. I interviewed Theodora during her first week as a patient of the clinic. However, I developed a relationship with her after our initial interview. Furthermore, I had numerous phone conversations with a few of the patients whom I had interviewed and grown close to.<sup>71</sup> These interactions continued sporadically for well over a year after I had left the clinic. In addition to chatting about their lives, I did some advocacy work on behalf of three of the patients I interviewed;<sup>72</sup> that is, I phoned solicitors, organised clothing donations, attempted to locate support groups and find information on tenancy rights and obligations.

The last of these conversations took place approximately a year and a half after I left the clinic.<sup>73</sup> At this time, I had stopped phoning the former patients and only heard from them when they called or texted me. I stopped phoning patients after having a few uncomfortable interactions: one when Alegra answered her mobile and pretended that I was someone else. I could hear several people around her and was worried that she felt the need to lie about speaking to me. I asked her to call me whenever she wanted to, but she never did.

### **Field notes**

Field Notes were written while Sophia waited for patients to arrive, while I was in the waiting room, and during all of the MDT meetings. I would only refrain from taking notes in the presence of the practitioners when we were having more intimate and informal chats. In order to contend with the medical terms

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<sup>71</sup> The patients whom I stayed in contact with after leaving the clinic were Celine, Elisabeth, Alegra and Evelina. These conversations do not form part of my research data.

<sup>72</sup> Eleanor, Alegra and Evelina.

<sup>73</sup> When Elisabeth phoned to let me know she was pregnant again.

used by the practitioners, I developed shorthand and would often have to ask Sophia or Ellen for clarification during our informal chats, as the practitioners would use abbreviations when speaking to each other. Fearing what might happen if I lost a notebook, and in order to keep track of all the practitioners and patients, I substituted their names with a prefix of either patient (P) or health professional (HP) and a unique number. For the sake of clarity and readability, I subsequently replaced these codes with pseudonyms when writing the thesis. However, pseudonyms have only been given to research participants who gave either verbal or written consent to participate in this project. Instead, when I write about the research participants' accounts of people in their lives, I refer to them either by a prefix and their unique number (i.e. Patient Number 1), or by a term that identifies their relationship to the research participant (i.e. "the research participant's husband" or "the research participant's former patient"). This will make it easier to distinguish between research participants and the people the research participants spoke to me about.<sup>74</sup>

Following this, I would record myself onto a Dictaphone, reading the notes I had taken during the clinic. The written notes were thus supplemented with my recorded observations which were more nuanced and would focus on all of the details that I had not had time to record in written form, but which were still fresh in my mind. I transcribed the recordings onto a word processor and they thus constitute my Field Notes. This process allowed me to provide a more meticulous and affect-laden depiction of my experiences and observations. Moreover, the process of recording myself speaking about the day's clinic was remarkably therapeutic. Here it is important to stress that while I was only an observer in the clinic, the act of witnessing so much anguish and hearing so many stories of atrocious acts of violence, death, destitution and hopelessness was upsetting. Speaking about the things that I had witnessed and heard was therefore an outlet for pent-up emotion, as well as being a method of data collection.

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<sup>74</sup> As discussed above, all research participants gave written and/or verbal consent to participate in this research project.

## Data analysis

I began analysing and coding data as soon as I had transcribed and imported into NVivo the notes I had recorded and written during and after the first clinic session I attended (Corbin and Strauss, 1990, p. 419; Seale, 2004, p. 243-244; Charmaz, 2006, p. 82).<sup>75</sup> Moreover, I wrote down questions that arose for me during this process and posed them to relevant people during the next clinic session. I continued to analyse data throughout the data collection period. This approach is in accordance with guidance provided by Glaser and Strauss (1968; Montgomery, 2010 p. 74).

When coding the data I decided to code by incident-to-incident, rather than, for example, line-by-line. Several things motivated this decision. First, the fact that the data I was initially analysing were my field notes meant that they were already in my own words (See Charmaz 2006, p. 53, for a discussion on why field notes are often better suited for coding “incident-by-incident”). Secondly, this method of coding was more conducive to the structure of each clinic session and the different areas I collected data in during the day. While each and every clinic session I attended offered unique experiences, my time in the sessions would usually be structured accordingly:

1. Waiting for Ellen, the HIV specialist midwife, in the antenatal clinics waiting room.
2. Chatting with Ellen in a consultation room while we waited for the other practitioner(s) to arrive.
3. Observing the MDT meeting. Three practitioners would usually attend.
4. Chatting with Sophia, an HIV specialist doctor, in her consultation room while we waited for patients to arrive.
5. Observing and often participating in patient consultations or waiting in the waiting room during consultations.

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<sup>75</sup> This was the first clinic session I attended after having received my research contract from the hospital's R&D office. As mentioned above, I had in fact attended clinic sessions prior to gaining ethical clearance in order to introduce myself to the MDT and discuss my research proposal. These meetings do not form part of the data used in this thesis.

6. Moment 4 and 5 would be repeated throughout the day, depending on how many patients would show up to the clinic.
7. Participating in a “debrief” meeting between Sophia and Ellen after the last patient left.

Various incidents within these moments were readily identifiable. For example, the practitioners would always recap and discuss the patients who were expected to attend the day’s clinic session. This would include her most recent biomedical interventions, tests, treatment plan and her social wellbeing during the morning meeting. It would not have been useful to code this data word-by-word or line-by-line as the data only made sense within the context of the meeting (Charmaz, 2006, p. 50).

### **Theoretical sampling**

Here I will describe how coding during this initial phase allowed me to begin to develop one of the most significant theoretical categories in this thesis. During initial coding I was struck by the import the practitioners in the clinic placed on finding out a patient’s immigration status. Moreover, during consultations and interviews the patients would inevitably bring up issues that related to either their immigration status or their country of origin. Following this, issues related to a patient’s immigration status permeated all of the data that I collected in each of the primary moments of data collection I listed above. Consequently, during data analysis I created the following codes in NVivo for “establishing immigration status”, “worrying about ‘home’ and ‘staying in the UK’”. The significance of these initial codes became apparent as I collected and analysed more data.

It soon became clear to me that there were other noteworthy codes fundamentally connected to the two codes mentioned above. Some of these related codes were “left behind family”, “partners’ immigration status”, “access to benefits”, and “relationship to family and/or community”. Further analysis emerged through the process of recording memos, collecting more data,

comparing data with data, and then comparing the data with the codes I created (Charmaz, 2006 p. 42). Then, while engaging in focused coding I tested “establishing immigration status” against more data (Charmaz, 2006, p. 42). The importance of the code held fast as did its connections to the other codes mentioned above. Eventually this process led me to create the theoretical code “diasporic issues” (Charmaz, 2006, p. 45, 63). This term signalled a theoretical direction that emerged from my data collection and analysis, and later, led to the theoretical concept of an “HIV diaspora”, discussed extensively in this thesis.

As a testament to the effectiveness of using grounded theory to analyse the data I collected, it is worthwhile to mention another code that I developed. This code was initially called “not wanting to be pregnant”. As more data was collected and analysed, this initial code developed into a theoretical one: “lack of bodily autonomy”. Data that pertained to this theoretical category concerned patients who had expressed a deep and often persistent unhappiness with being pregnant, and being or becoming mothers. Within this category, pregnancy and maternity were constructed as unfortunate and unavoidable biological consequences of being a woman. I mention this code because prior to commencing fieldwork, I had, perhaps naively, not anticipated that the patients in the clinic might not want to become mothers.

Furthermore, when patients first began to express unhappiness with becoming mothers to me, I had hoped that these feelings might have to do with a concern over the unborn babies’ wellbeing. Consequently, I had anticipated that these sentiments would disappear if and when the babies were safely delivered. This did not always happen, however. Therefore, if I had applied preconceived codes or categories to the data, and refrained from constantly interrogating my own assumptions, it is quite possible that these issues would not have become apparent to me (Charmaz, 2006, p. 46). So, the way in which the theoretical category “lack of bodily autonomy” developed is symptomatic of what Charmaz says grounded theory encourages: namely, early and continual “analytic thinking [that] keep researchers interacting with their data and nascent analyses” (2008a, p. 156).

## **Memo writing**

A crucial aspect of both the collection and analysis of data was the process of recording memos. I commenced memo writing as soon as I began the initial analysis and coding of data. Because of the writing difficulties I have due to dyslexia, I would record my memos on a Dictaphone while I was coding and analysing the data and then transcribe the recorded memos into NVivo. Like many other severely dyslexic persons, I would not have been able to capture my thoughts if I had tried to write them down directly. The process of memo recording and writing was fundamental to my ability to begin to develop focused codes, to think about the data, and the experience of being in the clinic. Moreover, keeping memos helped inform the direction I took when gathering additional data (Charmaz, 2006, p. 72). Also, recording and then transcribing memos added an additional step and another technology to the process of data analysis. The added step was introduced through the requirements of the technology. In this way, I would almost always augment and add to my recorded memos while I was listening to and transcribing them. Consequently, the memos as they were in NVivo, represent my thoughts over a period of time. Although there was some overlap, the memos I took were divided according to the following categories:

- Memos pertaining to the practitioners (what they said, how they interacted with each other and with me)
- Memos pertaining to the patients (what they said, how they interacted with me or other people present during our interactions, i.e. children and patients' partners)
- Memos pertaining to interactions between patients, practitioners and myself
- Memos pertaining to my thoughts about being in the field: the emotive dimensions of collecting data and interacting with research participants

## **NVivo**

All of the data collected for this project was analysed with the help of NVivo and to a lesser extent, Inspiration, which is a visual software program designed for people with dyslexia. The decision to use NVivo was motivated by the research training all first-year MPhil/PhD students had received in the Sociology Department at Goldsmiths, University of London. The program was available to me and seemed fairly straightforward when managing large amounts of data. In relation to this, Welsh argues that social scientists are often not able to make an informed choice when selecting which software package to use to manage their data because they lack the necessary expertise (2002, p. S2). Welsh's observations are relevant to my research and it is important to state that the training I had received in NVivo persuaded me to use the program as a tool to manage data and influenced my decision to adopt a grounded theory methodology. However, as Welsh contends, it is possible to use NVivo without also using grounded theory (2002, p. S2).

While Inspiration was not created as a tool for qualitative research, it proved to be valuable in that the program allows data to be organised into more organic two-dimensional structures. Data was entered into the programme after it had been coded and then assessed in NVivo and placed into "mind maps". These maps enable the user to visualise and manipulate data in a manner that is more compatible with the way in which many people with dyslexia, myself included, process information. Following this, I used Inspiration to create visual maps of the empirical material I had collected and analysed. The maps make sense to me in a way that a text-based software program could not.

## Afterthoughts

The grounded theory goal of generating theoretical analyses that fit empirical reality requires researchers to gain an *intimate familiarity with this empirical world*. Researchers cannot assess how well their analyses fit their data unless they have gained intimate familiarity with the studied phenomenon (Charmaz, 2008a, p. 162). (Emphasis added)

Fulfilling Charmaz's prescription would apparently require that both the researcher and the empirical world are static with clear boundaries. Instead, my impression of the antenatal clinic is that it is more akin to a sand dune in that it may retain a similar form, but it is never the same. Likewise, I have changed over the years and my relationship with the empirical world as I have captured it (as it was years ago) is consequently very different now. I argue that Charmaz's statement allows for differences between researchers but it does not directly engage with the differences in the same researcher over time, or with her changing relationship to her empirical material.

I was concerned about this issue. However, accounting for this problematic happened unintentionally because I interrupted my PhD studies for several years. When returning to the doctorate after this long break, I re-read the collected empirical material. Time away from the research along with changes that occurred in my life — most significantly, I had become a mother and had had personal experience with antenatal care in the UK (although not specialist HIV antenatal care) — meant that my interpretation and relationship to many aspects of the data had changed. An example of this is the way that I viewed breastfeeding. Many of the patients I had interviewed spoke extensively about breastfeeding. Consequently, I spent a lot of time exploring these issues with the patients. While I empathised with the patients' sadness over not breastfeeding at the time, I started to view the issues of breastfeeding in a much more emotive and visceral way because of my own experience of having a baby. Thus, re-reading all of the breastfeeding data I had collected and analysed left a different impression on me than it had done previously. Of course, what I have described here is a revised reading of the end product. In this sense, I was viewing a static empirical world, a world which was the same

as I had left it. It was my reading of that world that had changed because I had altered. So, re-assessing the data confirmed to me that while the theoretical categories I had created after the initial analysis stood fast, my emotive relationship to the data had not.

What I have described above reflects an argument made by Crapanzano. He writes that there is a tendency, or even a compulsion, to attribute the reality that has been negotiated between ethnographer and subject to the subject (1980, p. x), when in fact, the researcher is always changing in relation to, and as a result of, the subject(s) of her research and vice versa. In this way, the realities that are negotiated through the ethnographic encounter are negotiations between ethnographer and subject. Further to this, I suggest that these negotiations may continue even after the researcher leaves the field. The next section will consider some of the ethical constraints and dimensions of this study.

#### **Ethical Considerations and the Studies' Shortcomings: Who said what about whom and can I use what they said?**

Here I will directly address the question of whether it is ethical to include what the research participants said about people who had not given (verbal or written consent) to participate in this study. Any researcher who interviews health care practitioners about anything that concerns their vocation will undoubtedly hear stories about other health care practitioners and the practitioners' patients. Indeed the weekly structure of the clinic sessions — by this I mean the fact that the practitioners met and discussed patients before they arrived — meant that I from the very first day I attended a clinic session, I heard about people who had not given verbal or written consent to participate in the study.

Further to this is the fact that even when the practitioners spoke about patients or practitioners who had given consent to participate in the study, I would hear things about them that the person in question might not know were being discussed. For example, the practitioners sometimes spoke to me

about the difficulties they experienced working with a particular member of staff or about how badly behaved a patient's children were. In other words, the research participants told me many things about other participants that pointed to the fact that they each had different ways of experiencing and speaking about events that they both took part in.

Any researcher who interviews patients about their lives may very well hear stories about health care practitioners, the patients' family members, their sexual partners and children. In fact, the main thing that both patients and practitioners discussed with me were their relationships and interactions with other people. Of course this is not surprising considering that people are inevitably connected to other people. So, anything a person may say about their life will undoubtedly reveal information about those connections and the people to whom they involve. Consequently, I would constantly hear intimate details about people who had not consented to participate in my project. While what I have written above is unsurprising, the question remains as to whether or not it is ethical for a researcher to include stories about people who have not consented to participate in a study. I will address this question firstly by considering what these stories *are*, and then by what the implications might be of *not* including or seeking out these stories.

The qualitative interviews that I conducted with research participants produced an account of the interviewee's opinions (Byrne, 2004, p. 182). Moreover, the interview data was produced as a result of an interaction between the research participant and me (Mason, 1996, p. 36; Byrne, 2004, p. 181). Therefore, when research participants spoke to me about other people in their lives, I understood these stories to be *accounts* of their experience (Byrne, 2004, p. 182). To use Marsha Rosengarten's terminology to further clarify my point,<sup>76</sup> the stories interviewees tell about other people or events are "[approximations] achieved through [...] selective and reiterative practices. There [was] no stable" (Rosengarten, 2009, p. 28) third person or event that the interviewee is able to provide an objective description of. Mol

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<sup>76</sup> Rosengarten (2009) does not make this argument in relation to interviews.

describes the interviews she and her research assistants conducted in a similar way (2002). Thus, when Mol discusses Mr. Gerritsen's story she contends that his narrative uncovers something about "his feelings, his sense making, and his self-irony" (2002, p. 14), even though he spoke almost exclusively about his daughter and her new flat (2002, p. 13-14).

Consequently, in later chapters when I discuss events and people that the research participants told me about during interviews (and/or while I was in the clinic), they are not stable representations of a third party or of events that have taken place. Instead, they are my interpretation of an interaction that I had with a research participant. In other words, I describe my interpretation of my interaction with a research participant, during which they told me an interpretation of an experience they had (Charmaz, 2006, p. 25-26). Accordingly, Charmaz writes:

An interview is contextual and negotiated [...] the result is a construction-or reconstruction-of a reality. Interview stories do not reproduce prior realities. Rather these stories provide accounts from particular points of view that serve specific purposes [...] an interview reflects what interviewers and participants bring to the interview, impressions during it, and the relationship constructed through it (Charmaz, 2006, p. 27).

When describing the interviews I held with both practitioners and patients, it is important to mention the significance of the time I spent in the clinic in terms of shaping my questions and the dynamics between the interviewee and myself. The relationships that I developed with the interviewee before interviewing them undoubtedly helped me to explore very sensitive topics such as experiences with sexual and domestic violence. Moreover, and importantly, in the interviews I would often ask questions that encouraged the interviewee to reflect and expand upon topics that had been mentioned during consultations that I had taken part in (Charmaz, 2006, pp. 25-26).

What would be the implication for scholarship if it was unethical for a researcher to consider stories about people who were not research participants? In other words, how would a researcher go about investigating domestic violence if she was required to get the consent of both partners in the relationship being described by a victim of domestic violence? How would a researcher be able to explore practices of care from the perspective of health care practitioners or patients if she was required to track down and obtain the consent of any person mentioned? For example, would Mol have been required to gain the consent of the patient whose severed leg she discusses (2002, pp. 29-31), or the dead woman's next of kin described by a pathologist she interviewed (2002, pp. 45-46)?

As will become clear in later chapters, like Mol, I discuss the patient's partners, family members, children and acquaintances (none of whom agreed to participate in this project, or knew about it, as far as I am aware) and provide details of their behaviour, some of which is undoubtedly criminal and/or morally reprehensible. Moreover, I discuss the practitioners' stories about patients and other professionals who did not consent to participate in this project. Importantly, all of the discussions in the following chapters that consider these stories were collected from research participants who consented to participate in this study and the stories concern their lives, their truths, their version of events, as I have collected, interpreted, analysed and disseminated them.

### **Keeping my "researcher hat" on**

As I spent more time in the field the line between researcher and *friend* became less clear. For example, on two occasions I was asked if I wanted to attend the scheduled caesarean sections of patients. However, after discussing the possibility of doing this with one of my supervisors, I decided to decline the offers.<sup>77</sup> It is important to clarify why I was asked if I wanted to

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<sup>77</sup> I would regularly speak to my supervisors about issues that arose for me while in the field. Speaking to them about how best to conduct myself while in the clinic thus functioned as a kind of contingency plan for me.

attend the first operation. The pregnant woman in question had a young child who needed to be cared for while she was in hospital. The patient only had one friend who could either attend the surgery as her birth partner or care for her older child while the patient was in hospital. The possibility of my being the birth partner was brought up as a way of solving her problem. Thus, my role would have been that of a guest and supporter of the patient, not as a researcher. The concern was that I would have, in that situation, occupied the role of both friend and researcher and that this dual positionality might be intensely emotional and also ethically problematic. How could I stay in the role of researcher (i.e. “keeping my researcher’s hat on”) whilst witnessing and participating in what would undoubtedly be awesome events involving women I cared about? Moreover, how would it be ethical for me to attend the birth as a researcher when I had been invited as a friend? Walsh writes of the dilemma a participant observer may face in the following way:

The problem is that [the activities the participant observer engages in] carries the danger of reactivity and of going native through identification with the subjects of study, unless the intimacy created in social interaction is restrained by attempts to maintain the role of stranger on the part of the observer (Walsh, 2004, pp. 229-230).

Following this, it can be seen that while the methods that I used and the specific circumstances of the patients in the clinic elicited intimate and intense relationships and interactions, my prior commitment to be a sociologist and to produce a PhD thesis, and remain a “stranger”, delineated the extent and nature of my engagement with the patients in the clinic. While this may seem counter-intuitive and in opposition to the amassing of compelling data, it reflects the concerns outlined by Fraser and Puwar (2008) in relation to “*If no means no, does yes mean yes? Consenting to research intimacies*”.<sup>78</sup> They further write that this topic serves as a reminder

of the continued relevance of established research dilemmas: how are “boundaries”, between researcher and researched, proximity and distance, to be maintained? Where do the power relations lie? Is it an

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<sup>78</sup> The article in question was written by O’Connell Davidson.

ethics of research, or of friendship, that requires negotiating here (2008, p. 9)?

The possibility of attending the surgeries required me to assess the confronting nature of the request, and in this way, think deeply about what it would mean for me to take part, and how witnessing a birth may affect my relationship to the women in question and the clinic in general. Accordingly, I concluded that the scheduled C-sections would have been instances where it would have been difficult for me to maintain the boundaries between myself, as a researcher, and the women, as the researched. This is because I felt that the intimacy levels of being a birth partner would consequently make these boundaries difficult to maintain.

Moreover, the request(s) required me to think about the kind of access I was able to secure to the women's lives as a result of their apparent isolation. Had the patients had less need to confide in someone, most likely I would not have been able to have as much access to intimate details and events. I mention these concerns as a way of illustrating how, although often difficult, I attempted to act as an ethically conscientious researcher. However, the decision not to attend the surgeries meant I did not act in the way I would have, had I behaved as a friend to the patients. Had I acted as a true friend and consented to be a birth partner, I would never have considered the event to be a research opportunity.

The observations above were made possible by the passage of time and the distance I now have from those events. Admittedly, while I was in the middle of conducting fieldwork, the boundaries between being a researcher and being a friend (or perhaps it would be more accurate to describe my role as an emotive witness) were often blurred. How could they not be when confronted with the immediacy of many of the patients' needs? This could be thought of within O'Connell Davidson's terminology: in this way, my reluctance to describe myself as a friend to the patients I grew close to stems from the way my role as a researcher in the clinic and our respective positionalities outside of the clinic influenced the power relations between us.

According to O’Connell Davidson’s perspective, what significantly never changed in regard to my relationship to the clinic’s patients was the fact that they were always in tremendously precarious positions while I was not, and importantly, my research benefited from their insecurity. Hence, while both patients and practitioners were participants in this project, their fundamentally different positionalities within and outside of the clinic are reflected in every aspect of this thesis. Moreover, these differences (and my response to them) influenced what I chose to research and include in the dissemination of this project and what I left out and/or did not investigate. O’Connell Davidson considers similar concerns in regard to her friendship with her research subject:

The tension between the friendship and the research was most pronounced in relation to questions about what could and could not be treated as “research data”. Often, the knowledge I acquired as a friend was significant for various aspects of the analysis of prostitution that I was developing, but I felt it would be a betrayal of our friendship to record and publish it, and so I did not (2008, p. 54).

It is important to stress that I never developed the level of intimacy with the participants in this project that O’Connell Davidson did in hers. Nonetheless, her articulations feel relevant to me. Ellen, Sophia and I developed relationships wherein we discussed intimate details about our lives: issues we had had with our parents, schools we had attended, relationships to partners and friends, and, although the starting point had been HIV, pregnancy and the clinic — over the course of my time in the clinic I came to care about them and their lives outside of the hospital. I would argue that it was almost taken for granted that these discussions were not part of my research, or rather, that I was trusted to know when they could be and when they could not.

In response to this, I relegated the practitioners’ intimate details about their lives to the periphery of this research. The practitioners are consequently less exposed than the patients whose intimate narratives are at the heart of this

study. Therefore, in this thesis the practitioners' commitment to providing good care is discussed in regards to the practice that they engage in and not in relation to their motivations. It is important to point this out because, while I am keen to respect the health care providers' trust in me, respecting that also entails conveying their steadfast dedication to bettering the life chances of people affected by HIV. This is complicated to do without providing a more intimate portrayal of them, which would detail their political and personal motivations for working within the field of HIV medicine, and the remarkable personal sacrifices many of them had to make in order to provide the level of care they felt their patients required.

Moreover, I was, as mentioned previously, influenced by the way in which Mol distilled "good care" from "messy practice" (2008, p.10). Attending to health practitioners' life stories and sentiments do not feature in her rendition of good care. Consequently, and in accordance with Mol's approach, the practitioners' intimate stories about their lives have been filtered out of my final rendition of care in the specialist clinic. However, inversely from Mol, the intimate experience of being in the field and the intimacy I developed with the participants has not been siphoned away. Rather, these experiences and relationships were a central component in the collection of data for this project. In the next section I will discuss how certain things about me seemed to matter in various ways to the research participants.

### **Concerns with my relationship to patients**

Here I will consider some of my concerns about my interactions and relationships with patient participants. A difficult situation arose for me when I was at Celine's flat interviewing her for the second time. Her mother was with her when I arrived and Celine introduced me to her as a doctor from the London Hospital. When we were alone, Celine assured me that she knew I was not medically trained; however, she said it was better if her mother thought I was a (medical) doctor.

This proved extremely awkward after the interview when we were all playing with Celine's baby and her mother asked me a few specific questions about HIV transmission. I knew the answers to her questions but I worried about the fact that she thought I was a medical professional with expert knowledge on the matter. In response, I mumbled that I was a sociologist and that I was not qualified to answer her questions. Celine's mother's English was quite poor and I felt as if I had only managed to evade "outing" Celine's lie because of this. This exchange led me to decline an invitation to attend Celine's baby's naming ceremony. I was worried that Celine would expect me to lie to her friends and family about my identity and our relationship. Celine never phoned me again after I declined the invitation.

The encounter with Celine and her mother left me disconcerted. In hindsight I see that declining the invitation may have betrayed Celine's expectations of our relationship. These expectations may have arisen as a result of the intimate access she had given me to her life during her pregnancy. Declining the invitation might have confirmed to Celine that I did not place her life or needs in the same regard as my own (Geertz, 2001, p. 36). In this way, I have come to see that I did not offer a fair exchange for the things she let me hear and witness. In other words, while the second postnatal interview with Celine was the last time I *needed* her actively to participate in my research, this meeting might not have satisfied her expectations of me. Upon reflection I see that she might have stopped phoning me because I had betrayed an unspoken relationship both of us had previously been invested in maintaining (Geertz, 2001, p. 34). While I will never know what her expectations were, I believe that they had to do with the status I could have lent to her and her family had I agreed to *act* as a medically trained doctor who participated in her social events. Moreover, I believe that she wanted her mother to feel reassured that she was receiving such personal attention from a *real* doctor.

In *Doing Ethnography*, David Walsh makes note of the responsibility the researcher has towards the informers of the text and the need to close relationships appropriately with them (2004, p. 227). In regard to this, the way in which my relationships ended with the women was disconcerting. My

attempt to protect Celine led me to possibly offend her by rejecting the invitation. Moreover, being thus *cut off* and out of people's lives in which I had hitherto been so intimately involved, was upsetting. Nor could I resolve basic questions about their lives and wellbeing such as: was vertical transmission of HIV prevented? Did she finally leave her abusive partner, get deported; is she still alive? These concerns extended to all of the patients mentioned in the clinic while I was conducting fieldwork.<sup>79</sup>

The nature of care in the clinic and the legalities regarding access to medical notes meant that I could not expect to receive information about women once they ceased to be patients in the clinic. Following this, once a patient had her final appointment I would not hear about her again (unless she was mentioned for some reason by the practitioners). The full implication of being thus cut off from her narrative only became clear to me when I left the field and came to the realisation that I had been cut off from forty-eight women whose wellbeing I had been (to varying degrees) invested in. Therefore, while I take Walsh's advice seriously, it is difficult to know what an appropriate end to our relationships would have been.

### **Attending to patients' and practitioners' perception of me**

Another important aspect to my experience of doing research in the clinic was the way certain things about me — such as the colour of my skin, my accent, and my perceived nationality — seemed to be significant in specific ways to the patients in the clinic as well as to the practitioners. Therefore, in this section I will consider the way in which I “read” the patients' and practitioners' perception of me and discuss its significance to my time in the clinic. Brian Fay argues in *Contemporary Philosophy of Social Science* that the relationship between researchers and their subjects is not only perspectival but is also positional, meaning that the respective behaviour of both, ethnographer and subject, partially depends on their relative positions in regards to each other and on their mutual recognitions of each other's

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<sup>79</sup> The practitioners in the clinic may also become similarly “cut off” from patients.

positions (1996, p. 45). In what follows, I will describe a few instances wherein both the patients' and the practitioners' "reading of my positionality" seemed to become apparent and in this way discuss the reflexive nature of this project (see Hammersley, et al. (1983, p. 14); O'Connell Davidson (2008, p. 57)).

During one of our meetings<sup>80</sup> and prior to the commencement of my fieldwork, Anne, a consultant physician in the clinic, pondered on the effect my ethnicity and nationality might have on the patients. She explained that in her experience many HIV-positive patients of Black African descent preferred to speak to white professionals. However, she also said that it might be possible for me to gain some kind of insider knowledge because of my ethnicity and nationality: being black but a *different* kind of black.

Moreover, Sophia and I often discussed the status and effects of our "blackness" in the clinic and the way many patients expressed a reluctance to meet black (care) professionals.<sup>81</sup> However, and importantly, both Sophia and I felt these patients' concerns stemmed from the fear that we might know them or members of their communities outside of the clinic. Once it was confirmed that we moved in different social circles, the reluctance of meeting us was no longer present. In this way, the colour of our skin functioned as an alert to the fact that they might know us outside of the clinic, while in my case my accent often dispelled these concerns.

Indeed, all of the patients that I interviewed broached the subject as well, usually to speak of my perceived "American-ness" as being one of the reasons why they eventually felt comfortable with me, *despite* my being black. Furthermore, Sophia told me that patients would often ask her where I was from, prior to consenting to having me attend their appointments. Below is an extract from my Field Notes that concerns the questions some patients asked Sophia about me. The patient in question had seen me in the waiting room and knew that I was the person Sophia was referring to when she asked the patient if I could sit in on her appointment:

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<sup>80</sup> This meeting took place after I had received ethical approval to commence the study.

<sup>81</sup> Sophia is British of Black African descent.

Sophia said that the last patient had asked if I was from here: “is she from London”; as soon as Sophia had told her that I was from the US and Sweden she was ok to have me sit in.<sup>82</sup> Sophia said that she felt that my accent worked to my benefit; people did not “read” me as being from “here” (Field Notes, 6 August, 2008, p. 14).<sup>83</sup>

Not mentioned in the notes above is the crucial fact that I was not read as a *black woman* from *here*, i.e., a Black woman of either African or Caribbean decent. It is here that the work of Fassin becomes particularly useful. As discussed previously, Fassin argues that it is important to consider the way in which the subjects of our research are inscribed within various historical trajectories, although he does not in the same way consider the significance of the historical trajectories the researcher is inscribed within. It is, however, useful to do precisely this in order to fully appreciate the way judgements about people are made. It is, as Abu-Lughod, referencing Dwyer, points out: anthropologists are not outsiders to the societies they study. Rather they are in constant “historical and social relation” to them (1989, p. 276). Accordingly, for many of the patients it seemed as if my “American-ness” alleviated the concerns that had arisen from my “blackness”.

### **Shortcomings in the study**

When planning what to disseminate in this thesis, I have been concerned about the fact that the practitioners in the clinic would be able to identify each other. Thus, honouring the agreement I made — to allow Anne to read everything I write that uses the data I collected in the clinic, prior to publication, and to make anything I might publish available to the MDT— has led me to be very careful about how I discuss the practitioners in the clinic.

Moreover, the identities of the practitioners in the clinic are not fully protected despite providing pseudonyms to all of the research participants. Anyone reading this text could easily figure out which hospital I was based at. This is

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<sup>82</sup> None of the patients ever remarked on the fact that I am also Swedish.

<sup>83</sup> I speak English with a North American accent.

because the description of the specialist clinic that I provide makes it easily identifiable amongst other HIV specialist antenatal clinics in the UK. Thus it is ostensibly possible to deduce the names of the practitioners mentioned in this thesis. It is important to mention that true anonymity within the context of doing HIV research within the NHS in the UK (and especially London) would be difficult to achieve because of the relative “smallness” of the HIV medical field and the fact that HIV specialists within various NHS trusts in London often have professional relationships with one another.

Hence, anyone working with HIV within the NHS in London would undoubtedly know all of the HIV specialists at any particular trust. These concerns were brought up on several occasions while I was in the clinic. Ellen made jokes about how she and the other professionals would read through my published thesis and try to figure out who said what. So, I could argue that the practitioners were aware of the risks they took when agreeing to partake in this research. Moreover, I could interpret Ellen’s joke as acceptance of this fact. However, this does not feel right. Instead, I made the decision not to include explicitly personal information that the practitioners disclosed to me during my time in the clinic. Moreover, I have chosen not to discuss issues related to the practitioners’ relationships and interactions with each other. In this way, I hope that they will all feel that while I cannot entirely protect their anonymity, I have not disclosed information that in any way compromises their relationships to each other or their positionality within the clinic. Editing out the practitioners in this way is thus, as mentioned before, a necessary limitation to this thesis.

These restrictions were implemented after the fieldwork and initial analysis of the data was finished. Therefore, concern over the practitioners’ opinions did not in any way interfere with the collection or analysis of data. Rather, their opinions (as I imagine them) have come to matter to me when deciding what to write about in this thesis. In other words, data was collected and analysed freely, but I do not feel that I have the same freedom when choosing how to disseminate my findings.

For example, one of the important theoretical categories that developed through my data collection and analysis related to the organisational structure of the clinic. In regards to this, I was interested in the way information about patients was collected, discussed and shared. Consequently, I investigated amongst other things, how notes were kept (or not), and how they were shared between different clinics (or not). Another theoretical category that emerged concerned the power dynamics between the practitioners in the clinic. I became interested in the way different health care providers spoke about and interacted with each other. However, on reflection, I have decided not to include these topics. This is because the benefits of including such a discussion did not outweigh the risks for my research participants (Ali and Kelly, 2004, p. 125). The exclusion of any deeper analysis of the practitioners' activities is a necessary and unavoidable shortcoming in this study. Omitting this analysis points to the fact that researchers are not autonomous, nor is the research that they produce.

## **Conclusion**

In this chapter I have outlined some of the methodological issues that I dealt with while studying HIV and pregnancy in the clinic. While the previous chapter explored, amongst other things, the way Annemarie Mol's theoretical contributions influenced the framing of this thesis (that is, I draw on her arguments which state that bodies are ontologically multiple, that conditions emerge out of practices as well as the notion of "good care"), in this chapter, I have considered instead Mol's and Mol's and Law's methodological approaches and the ways they are consistent with their theoretical arguments — as well as their approach's influence on the methods used to conduct this project. Their approach influenced my methodology and enabled me to discover how HIV and pregnancy were enacted in practice in the clinic.

Moreover, in this chapter, I have considered Julia O'Connell Davidson's discussion on the significance of a researcher's emotive connection to her research participants. O'Connell Davidson's argument allowed me to reflect

upon the way it felt to be in the clinic and conduct a research project in a highly emotional environment with participants who were often vulnerable. Thus, in this chapter I have shown how her work influenced my attempts to behave as an ethically sensitive researcher.

Further to this, I have discussed how my methodological approach has been influenced by Clifford Geertz's argument that (a researcher's) thoughts should be visible so that their ethicality can be assessed (2001, p. 21). In this chapter and in the rest of the thesis, both Geertz's and O'Connell Davidson's arguments have consequently encouraged me to include my thoughts and feelings about the research process and my relationships to participants. Moreover, this chapter has considered some of ethical concerns and shortcomings of the study.

## Chapter Four: Biomedical Possibilities and Complications

There is a real capacity to cock up substantially, and it puts a different spin on how you approach it (Interview with Anne, a consultant physician, 11 March, 2009, p. 12).

Having successfully decoupled HIV from death, ART and appropriate care have made the prevention of vertical transmission the norm in the UK. However, in this chapter I will show that the practitioners are now placed in a position where a false move on their part may cause their patients and their (unborn) baby irrevocable harm. I will argue that this fact is a constant burden for the practitioners. Moreover, negotiating this burden, which in this chapter is evidenced as the unwanted (imagined) possibilities of the biomedical technologies and medicines on offer to the practitioners and their patients, is an essential part of the care that they provide. Thus, this chapter will show that the practitioners' dependence on technologies that are vital to the successful prevention of vertical transmission of HIV may simultaneously complicate their ability to care for their patients. In other words, it is assumed that the practitioners are able to rely on the technologies to produce the "right" results, when in fact they know from practice that the technologies are not necessarily reliable. It will become clear in this chapter that what is ultimately at stake for the practitioners in the clinic is the future health of the postnatal mother and her baby. In this way, the chapter will explore what happens when the practitioners care for the patient as she is now — taking into consideration the patient as they *hope she will become*.

The approach taken in this chapter is drawn from Annemarie Mol's argument (discussed in Chapter Two) namely in that thinking about the way an illness is *done* enables reflection on how the illness's identity within a particular environment is tenuous, variable and in need of continued and sustained maintenance (2002, p. 23). I have also drawn from Mol's and Mol and Law's approach to fieldwork, discussed in Chapter Three, and taken inspiration from

Mol (2008) who has encouraged me to explore the notion of good care in the clinic.

Influenced by Mol and Law, I have analysed the practitioner's behaviour so that I could ascertain what the practitioners felt was required of their patients in order for the MDT to prevent vertical transmission of HIV (2004, p. 47). Moreover, I was interested in understanding what the practitioners felt their patients needed to do in order to "[appropriately engage]" with relevant technologies (2004, p. 47). To this end, I will discuss some of the "treatment practices" the practitioners used to discover what HIV was (2004, p. 46). And while Mol and Law were interested in exploring the effects various methods of caring for people with a disease (hypoglycemia) had on the diseased body and how the patient lived her life (Mol and Law, 2004, p. 55), I am interested in exploring the effects various methods of caring had on the practitioners and their understanding of the care they provided for their patients. Moreover, I am interested in investigating what the practitioners felt their various methods of care had on their patients' bodies and lives.

The chapter is organised as follows: the first section is about how some of the technologies the practitioners depend on to inform their care are suspected as *misrepresenting* HIV. This section will argue that the technologies' unreliability is directly related to the clinic's patients' position within the HIV diaspora. The chapter will then consider the notion of a filter as discussed by Nancy Scheper-Hughes (1993) and argue that some of the technologies used in the clinic tell us more about *our* beliefs than they do about a patient's HIV. After this I will consider what Marsha Rosengarten (2009) would call the "generative capacity" of some of the technologies used in the clinic. Finally, I will discuss some of the problems with the idea of patient choice and argue that choice as an activity as encouraged in the clinic has its limitations because of the practitioners' concerns with the patient and her baby's future.

The empirical material in the chapter is based on my observations of patient consultations, MDT meetings, and discussions and interviews with practitioners (specifically Anne, a consultant physician and Ellen the HIV

specialist midwife). As mentioned in the previous chapter, all research participants who gave either written or verbal consent to take part in this project have been provided with pseudonyms.

**Contending with specific technologies' inbuilt knowledge of HIV- filtering information: Misreading foreign viruses**

In the antenatal clinic, the viral load assay reads HIV inside a pregnant woman's body by measuring the amount of virus (HIV Ribonucleic acid (RNA) particles) in her blood. During my time in the clinic it became clear to me that the practitioners were concerned that the assays produced inaccurate interpretations of their patients' virus, which might adversely interfere with their clinical practice. This is significant because assessing a patient's blood on an assay is a vital first step in caring for her and her unborn baby.<sup>84</sup> Essentially, the patient's blood is turned from biological material into information that is sent back to the clinic — information which is now out of date. For example, the amount of virus that was in the patients' blood sample might not correspond to the amount of virus currently in her blood and it is then used by the practitioners to help them create a treatment plan for the patient. The intention is that the information will assist the team in altering the virus's course in the patient's body by preventing it from multiplying and from ultimately being transmitted to her (unborn) baby. There are, however, many things that can complicate this initial task.

Several of the practitioners explained to me that they suspected the results from certain viral load assays had provided them with inaccurate information. Indeed, on numerous occasions the suspicion that the viral load results they received for patients were in fact inaccurate was confirmed. They clarified that the ROCHE assay occasionally under-quantifies the viral loads of their patients, making them seem healthier than they actually are (de Ruiter et al.,

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<sup>84</sup> For a more detailed discussion on viral load assays, please refer to Chapter One.

2008, p. 465). ABBOTT is therefore the practitioners' preferred assay, as they believe it is more *sensitive* to their patients' viruses.<sup>85</sup>

Thus, if a particular blood sample is processed through one viral load assay rather than another, the viral load may not be accurately quantified. In other words, the technology has been made to be able to distinguish between what are considered to be foreign and native forms of the virus.<sup>86</sup> If incorporated into practice, this inaccurate *reading* of a patient's virus could complicate the patient's care and potentially increase the risk of vertical transmission of HIV. Therefore, while the process of assessing a patient's viral load might initially appear to be simply about acquiring and coordinating information, it is also about different understandings of HIV and how these are *built into* the technologies available to the clinic. A similar argument has been made by Flowers and colleagues who contend that a positive HIV antibody test has the ability to generate identities in addition to confirming the presence of a virus (2006, p. 120).

The problems outlined above could be thought of in relation to how Didier Fassin (2007) discusses the significance of place, space and movement. Fassin makes the suggestion that people are embedded within particular locations and limited to the possibilities accorded to their bodies within that location.<sup>87</sup> Consequently, viral load assays built to be sensitive to subtypes that are considered more common in the northern hemisphere serve to "exclude" people from the southern hemisphere (who have an "unrecognised" subtype of the virus) and who have managed to change geographical locations. To reiterate, the geographical division between people with access to advanced life-enhancing biomedical technologies and those that do not have access can be maintained, even when the geographical discrepancies

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<sup>85</sup> The practitioners within the antenatal clinic were reluctantly dependent on an inter-NHS trust outsourcing of their patients' blood as the London Hospital did not have its own full time virologist. In the first instance the London Hospital sent blood samples to a virology team within a different NHS Trust in the city. For a further discussion of viral load assays please see Chapter One.

<sup>86</sup> Please see Chapter One for a discussion on the way various sub-types of HIV-1 have been allocated specific geographical locations where they are understood to be most prevalent (Heimer, 2007).

<sup>87</sup> Please see Chapter Two.

are dissipated. To put it more succinctly, when people who would normally not have access to advanced biomedical technologies (because of the geographical and/or political location or trajectory they are inscribed within) *relocate* themselves and inhabit the position of people with unrestrained access, the way the technologies have been made might still impede any benefit.

Therefore an HIV-positive person's original geographic location, or rather the location in which she acquired her infection (assuming she had with the subtype thought to be prevalent there) could, in this instance, delineate her inclusion and extent of her participation in various processes of care available in the clinic. In other words, fully partaking in and benefiting from the different technologies and interventions available in a particular geographical location may require more than simply having access. From this follows the fact that people living with HIV within the same location may not experience the same transformative possibilities promised by the availability of advanced HIV detection and assessment technologies (Flowers et al., 2006, p. 118). The implications of this are that inequalities between different geographical locations are, in my example, maintained even when geographical distance is no longer an issue. Hence, even when patients who are incorporated within the HIV diaspora are *offered* the same access to particular kinds of biomedicines and technologies, their ability to be enhanced by these inventions may be curtailed by the way in which the technologies have been built to *not* detect certain kinds of differences that the clinic needs them to do — in this instance, different subtypes of HIV. Consequently, the technologies in question make and maintain other kinds of differences such as access to treatment, locations and futures less affected by HIV, or in the case of babies born to HIV-positive mothers, futures free from HIV.

An additional complication in this scenario is how the practitioners felt patients may respond to their viral load results. It is important to clarify that I will not provide an exploration of the actions or motivations of a patient in what follows. Instead, my discussion of Patient Number One (drawn from

conversations with practitioners and from here on referred to as P1)<sup>88</sup> should be read as an exploration of the practitioners' understanding of a patient they encountered in the clinic. While P1 and I had many friendly interactions with each other in the waiting room, I never interviewed her or observed her consultations.

P1 was in the second trimester of her fifth pregnancy and had recently been informed that she was HIV-positive. Observing her behaviour in the clinic, the practitioners explained that they were not convinced that P1 believed their diagnosis. In regards to this, P1 told one of the practitioners that she was under a spiritual curse and that in order to overcome it, she would have to "trust in God" and avoid any mention of HIV. P1 explained to Sophia, a practitioner, that speaking of HIV in her presence invoked the Devil and affirmed the curse (Field Notes, 4 February, 2009, pp. 3-4).

Consequently, P1 often refused to be introduced to new members of the clinical team or allow them to be involved in her care. Moreover, she would not attend any appointments if they were held at the DOSH because an evil spirit lived there. Her non-compliance severely complicated the care that the practitioners wanted to provide her with. Furthermore, they were concerned that she would eventually abscond entirely from their supervision. In order to prevent this from happening, the practitioners decided to reorganise their clinical practice to accommodate her. They allowed P1 to dictate where and when her care would take place and which practitioners she would see.

The practitioners were very cautious with her throughout her pregnancy, spending a lot of time trying to figure out how best to negotiate her conditions with their agenda. During a meeting, Sophia expressed that the incorrect viral load results were particularly problematic when dealing with a patient like P1, who was, according to Sophia, under the impression that she had been healed from HIV based on her results from the ROCHE assay. Sophia said that explaining to a patient why it looked as if they were HIV-positive on some

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<sup>88</sup> P1 was from the Congo.

machines while not on others was very difficult (Field Notes, 4 February, 2009, pp. 3-4).

On a very practical basis the requirements of HIV and pregnancy (as they are perceived by the practitioners) necessitate that when making decisions about the patients' care in the present the practitioners should consider the feelings they think their patients and their (potential) offspring may have in the future. This is particularly significant because it alludes to some of the complexities that may occur in the specialist clinic if a pregnant patient resists or refuses the practitioners' desired care plan. Thus, practitioners in an HIV specialist antenatal clinic would base their care decisions on the patient as she is now *and* on what they hope she and her baby might become in the future. In a more abstract sense, they are consulting with a real present time patient, with her future self, and with her future baby, as the practitioner imagines them to potentially become if care is successful. Imagining and thus considering the future in this way is an important aspect of the care that the practitioners attempt to provide their patients with.

Moreover and in this context, the viral load assays' ability to produce information about HIV has the potential to cause problems in the clinic on several levels. As with the example of P1, what the practitioners fear is that she will interpret the technologies' inadequacies as a sign of having been cured of HIV. However, it is important to point out that the technologies' capacity to generate information about HIV is not always considered to be bad; for example, in situations where the practitioners never question the viral load count or when they deem it is correct and vertical transmission is prevented and mother and baby are *well* at the final postnatal appointment, the technology could be thought of as having the potential to generate positive effects. This is because the technology provided crucial information that the practitioners then used to inform all aspects of the patient's care and finally prevent vertical transmission, thereby securing the relative wellbeing of their patient(s). Thus, it can be seen that when all goes well, the exactitudes and possible merits of the multiple components involved in the patient's care are not necessarily analysed and assessed individually. This might only be done

when things go badly or are suspected of potentially going badly. However, and importantly, the practitioners are well aware of this as will become clear later in this chapter.

The viral load assays used by the antenatal clinic in the London Hospital were specifically attuned to assessing sub-types of HIV that were (and are) most common in white gay males in the UK. These assays pre-date the changing demographics of HIV in the UK that has seen black Africans, in particular black African women, as being disproportionately affected by HIV. Consequently, the technology includes histories of the pandemic, its movement through time from place to place and between bodies. Accordingly, P1's case reflects an argument I made above, namely that the process of assessing a patient's viral load may create different understandings of HIV. In other words, despite having more or less uncontested access to the most advanced biomedical technologies, medicines and information, the practitioners constantly labour with the knowledge that these technologies may in fact obscure what they are ostensibly meant to divulge, manage and access. Moreover, the practitioners contend with this knowledge while negotiating the different understandings patients have of their bodies and the status of their HIV infection.

### **Compensating for unreliable technologies**

In Chapter Two I introduced the concept of a filter and argued that the practitioners function as filters within the clinic. Here, we can see that there is a further complication, namely that the information the practitioners — as themselves *filters* — have access to may also be *filtered*. The issues discussed above are evocative of Nancy Scheper-Hughes' (1993) work, insofar as the discussion above illustrates how certain knowledges of the patient's body could potentially remain entirely hidden unless they are actively "sought out". Accordingly, the technologies available to the clinic are "not neutral" nor do they produce "pure sources of data" (1993, p. 292). Rather, the technologies like the "public records" discussed by Scheper-Hughes

“reveal a society’s particular system of classification. They are not so much mirrors of reality as they are filters” (1993, p. 292). This is meaningful and I argue that one of the crucial tasks the practitioners adopt is the constant anticipation of and supplementation for potentially “hidden” information. Using Scheper-Hughes’ language further to clarify this point, the practitioners place tremendous significance on the information that the “filters”<sup>89</sup> have made (or are suspected of having made) (nearly) inaccessible by sifting it out and away.

Moreover, the inaccurate reading of a patient’s virus, discussed above, points to a crucial problem that stems from the healthcare practitioners’ and, indeed, the “HIV biomedical field’s” reliance on biomedical technologies. Thus, while the practitioners have located the virus as being in a patient’s body, the actions they carry out on the virus, its movement through time and space, within and outside of the host’s body, together with the technologies used to identify it within each of these contexts, always places its *identity* (by this I mean, for example, the viruses genotype and the severity of the infection) under question, according to the practitioners. Following this, in order to provide care to the patients within the clinic, the practitioners must anticipate the varying interpretations of these technologies and prepare ways of contending with them. Anne, a clinician in the clinic, expands on this during an interview:

We have turned the viral load tests and the genotype tests into a holy grail of fact and they’re not that factual. They are constructions, particularly the resistance tests; they’re constructions of ideas about what resistance might be; they’re being worked out in past time; they’re out of date before you start looking at them for viruses that are geographically distinct from ours. We have something that we invest a certainty in and we model our thoughts and we marshal our clinical actions against a level of certainty which then proves to be wrong; it

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<sup>89</sup> In this particular instantiation the filters in question are the viral load assays.

undermines what you thought you were doing (Interview with Anne, a consultant physician, 11 March, 2009, pp. 10-11)!

The variations in the discernment, reading and interpretation of the virus correspond therefore to what would effectually be multiple versions of the virus which could each have corresponding ways of being thought about and enacted by the practitioners and their patients. In other words, the intangibility of the virus is potentially increased and perpetuated as a consequence of the way it is done by the viral load assays.

These issues are further complicated by the fact that not all of the practitioners that care for the clinic's patients will necessarily have access to the same viral load results. This complication became apparent to me during clinic one day when Ellen expressed her concern over the accessibility of her patient's results. She explained that a patient's initial results were zero; however, this proved to be inaccurate when her blood was retested on a different assay<sup>90</sup> (Field Notes, 18 February, 2009, p. 7). Ellen's fear was that the patient might be cared for as if she was an HIV-positive pregnant patient with an undetectable viral load<sup>91</sup> when her viral load was in fact detectable, thus potentially jeopardising her life and the future life of her unborn baby. Therefore, from the practitioner's perspective, the multiplicity that is created as a result of the different assays and their results can "remain" in the hospital and have effects even after the MDT have discredited the initial assay's results. Moreover, it can be seen that inaccurate viral load results are imagined by the MDT to have the potential to intercede into clinical practice in the future, in the sense that the practitioners fear that at any point in time they will discover that their procedures and practices in the past were in fact detrimental to the future health of their patients. In other words, the

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<sup>90</sup> Please see Chapter One for a discussion of the significance of the different viral load assays used to assess the clinic's patients' blood.

<sup>91</sup> As mentioned previously this means that the amount of copies of virus per millilitre of plasma is below the *lower limit of detection* on the particular test assay being used. It is important to note that different assays have different lower limits. Thus, a sample may be undetectable on one assay but not on another (de Ruiter et al., 2008).

practitioners' concern about the various technologies that they use does not necessarily change their practice — but it does make them feel unsure about their practice — and their ability to ensure futures less affected by HIV for mother and baby. Thus, the practitioners can never feel entirely confident that the care they provide (and/or provided) their patients with was in fact good care, despite their best intentions and efforts.

Problematically, from the practitioners' point of view, by the time the practitioners would discover that they had in fact used bad information to inform their practice it might be too late to rectify the mistake. In this way, the inaccurate viral load results would become part of the way in which HIV was enacted in practice. Consequently, I suggest that the possibility of this happening in the future is feared by the healthcare practitioners. This fear in combination with their mistrust of some of the (biomedical) technologies available to the clinic causes a constant foreboding. Here it can be seen that the work the practitioners do involves anticipating events and entities that have not (and may never) become enacted in practice.

### **Dealing with the generative capacity of biomedical technologies: Displaying HIV**

Here I will further explore how practitioners in the clinic contend with the knowledge that the biomedical technologies they rely on have a generative capacity.<sup>92</sup> The practitioners are actively aware that HIV as it is displayed in the clinic is not, as Rosengarten has argued, “unaffected by technologies involved in [its] representation” (2009, p. 24). However, and importantly, I will argue that according to the practitioners, this happens because they believe the technologies available to them are inadequate to the task. Furthermore, they believe that *better* technologies might not have this effect on HIV. Accurately assessing a patient's HIV is thus, for the practitioners, a matter of acquiring and coordinating various components that are able to display HIV as they imagine it *is* in a patient's body, unaffected by the technologies currently

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<sup>92</sup> See Rosengarten (2009): HIV interventions, Chapter Two.

involved in its representation. This section will demonstrate how this belief participates in the way in which the problem of “HIV” is framed, understood and potentially confronted; in other words, this belief delineates the practitioners’ efforts to combat HIV in the clinic. Moreover, this belief is the reason why the practitioners embrace a constant sense of unease in relation to their medical practice.

The healthcare practitioners act on their patient’s virus even though the information they have about the virus is, as discussed previously, potentially out of date and highly suspect. However, immediate action is nonetheless required in order to prevent the virus from being transmitted to the unborn baby, and thus becoming what the practitioners fear it may become in the future (i.e. out of their control) if left untreated. Consequently, the practitioners suspect that the practices in which they engage in have the ability to facilitate the creation of “inaccurate” bodies and viruses. However, while practitioners may agree that they are implicated in what happens to the virus within the clinic, they also operate with a belief that there is a virus external to practice. In relation to this Rosengarten argues that

the virus, as it appears, is an approximation achieved through highly sophisticated but nevertheless selective and reiterative practices. There is no stable object that we refer to as “HIV” or “the virus”. On the one hand, it is revealed by science as having altered over the course of the epidemic as a consequence of its movement and mixing with bodies and now, especially, with ARVs and associated observational technologies. On the other hand, though, there is a certain abstracting out of what is involved in this mixing — on the part of science — in order to achieve a seemingly stable object *of study for intervention* (Rosengarten, 2009, p. 28)(Emphasis in original).

Taking immediate action does not eliminate the feeling of trepidation that the practitioners struggle with. This is because taking action on a patient’s virus entails implementing a treatment regime that the practitioners know might alter their patient’s body in such a way that it will eventually be deemed

inappropriate, if the *true* identity of the virus is proven to be different from their present-time understanding of it. In order to stress this point, the practitioners view HIV technologies as potentially obscuring their access to the patient's *real* virus (as they understand it to exist within her body but never observable or assessable in real-time). As discussed earlier, this is because the technologies are known to have the potential to facilitate the creation and endorsement of treatment regimes that will increase (or decrease) the likelihood of vertical transmission and mortality. In other words, the technologies are known to have the potential to irrevocably harm (or "heal") the practitioners' patient cohort.

This brings to mind Rosengarten's observation mentioned previously: that advanced biomedical medicines, specifically antiretroviral drugs (ARVs), have led to the decoupling of HIV and death (2009, p. 3). In regards to this, Anne explained that a consequence of the change in prognosis for HIV-positive people has been that practitioners now know that the care decisions they make could potentially cause harm to their patients and their (unborn) babies. For Anne, when death is no longer the inevitable outcome for an HIV-positive patient, the potential impact of all aspects of the care she might provide her patients becomes more significant. This is important and illustrates the practitioners' tremendously difficult task of negotiating the *porous line* between attempts to provide care and inadvertently causing harm.

The early days of the epidemic, when you were doing your best and actually the ability to do harm was relatively limited, it sounds very brutal, but now there is a real capacity to cock up substantially and it puts a different spin on how you approach it. If you get the treatment wrong at this point and you end up with an infected baby or you get the treatment wrong and the mother gets resistance,<sup>93</sup> you're dealing with something much more complicated and if you're not up to speed, you know it's a big deal. I think it's changed things quite a lot (Interview with Anne, a consultant physician, 11 March, 2009, p. 12).

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<sup>93</sup> Drug resistance refers to HIV's ability to continue mutating and reproducing despite being exposed to Antiretroviral Therapy (WHO, 2014).

Anne's articulations are important in regards to the notion of good care in the clinic and add another dimension to the decoupling of HIV and death, namely in terms of how the increased life chances of people living with HIV have drastically altered what is at stake in the provision of care.<sup>94</sup> Consequently, the provision of good care now concerns the maintenance of (a good) life and not the management of (a decent) death. Moreover, what is shown is that the interventions that HIV is subjected to, both within the patient's body (as it exists as a material object unobservable in real-time) and external to it (as it exists as a "seemingly stable object") (Rosengarten, 2009, p. 28), together with the technologies used to identify it within each of these contexts, participate in the materialisation of HIV but they also place its *identity* (as the practitioners believe it to exist prior to its present time appearance) under constant question within the clinic. In other words, the practice and technologies that participate in the *representation* of HIV within the clinic are suspected, by the practitioners, of potentially displaying inaccurate renditions of the virus. Despite this, and as discussed above, these renditions may be incorporated into further clinical practice.

Ellen spoke about the possibility of this happening in a meeting with Sophia and Anne, during which she discussed how the practitioners in the clinic tended to respond to viral load results from the ROCHE assay from patients on treatment, which stated that the patient's viral load was undetectable. The following is an extract from my field notes and paraphrases Ellen's articulations on the subject:

If someone is on treatment, then we get eased into the belief that they are undetectable; but they might not be, we are being lulled into this sense of security with these patients. They might not be undetectable at all but we just expect them to be because we have these expectations that the medicines will work on their bodies in a certain way, but that might be a false expectation (Field Notes, 4 February, 2009, pp. 5-6)!

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<sup>94</sup> Flowers (2010) considers some of the new uncertainties for people living with HIV that have been made possible because of their increased life changes. Persson (2013) discusses the impact these developments have on the lived experience of people living with HIV.

Accordingly, if both the technology and the practitioners' assumptions about a patient's health are in "agreement" there is no other "system" that would "detect a fault". Therefore, a technology's negative generative effect would be allowed to fester. Hence, Ellen is expressing a fear of a reality that has not yet transpired. While the reality Ellen fears may never take place, her concern matters nonetheless because it influences the way practitioners use their imagination in combination with their knowledge and experience in order to anticipate future problems and consequently (attempt to) prevent them from ever occurring. Thus, the MDT's mode of operation in the clinic is to embrace a constant sense of unease and suspicion towards the biomedical technologies on offer to them. Conversely, as will become clear in the next section of this chapter, they cannot allow their patients to have the same scepticism if and when they fear it might lead them to disengage or refuse care.

Furthermore, many of the practitioners spoke with some nostalgia about the time prior to the introduction of certain technologies into the field. With regard to this, for example, Anne contends that clinicians' over-reliance on biomedical technologies is something new and problematic.

We worked out with patients what to do without that test. Then the technological stuff came along and moved HIV medicine into a different area and then you find that it's not substantiated in fact, and it undermines all sorts of things that you thought you knew (Interview with Anne, a consultant physician, 11 March, 2009, p. 11)!

Here, it can be seen that the practitioners have a new way of working which entails a dependence on technologies that were not available previously. These new technologies have generated different procedures and practices in the clinic. Furthermore, they have transformed the way in which the practitioners *know* and *understand* HIV, in that these technologies have changed what HIV *is*. Consequently, these technologies enabled the discovery of new entities that did not *exist* (as negotiable and identifiable

objects in the clinic) prior to the technologies' introduction into the clinical environment.

Here it is important to reiterate that the virus is understood by the healthcare practitioners to have a *true* identity, however inaccessible this identity appears to be. For the practitioners in the clinic the virus' potential (future) effects on the body of the patient and her (unborn) baby evidences the virus' reality. Hence, the practitioners would argue that there is a reality to which truth refers and that accessing this *pure truth* is a matter of making, having access to, and engaging, for example, *better* and more sensitive biomedical technologies. This belief is, as Rosengarten (2009) has argued, widely acknowledged to be true within the scientific community and it subsequently participates in the materialisation of HIV in the clinic. Thus, this belief plays a significant role in the way the problem of HIV is conceptualised and confronted both socially and biomedically within the clinic.

On the basis of what I have described above, it seems that there is a worrying problematic at work. Although medicine sets out to achieve prevention, the very object to be prevented remains elusive. I suggest that it is within this problematic that the significance of the practitioners' work becomes discernable in that they attempt to make it possible for their patients to be cared for, despite the shortcomings of the technologies available to them. The next section will further consider the care the practitioners provide.

### **Problems with choice**

In this section I will contemplate how the practitioners perceive their patients' resistance to care. I will argue that the healthcare practitioners allow for a certain amount of divergence from their overall plan of care, but that when pushed, they do have limits and these are imposed because of their concern for the unborn baby and the postnatal patient, as they imagine her to be and have the potential to become. Moreover, the significance of the idea of a good (becoming) mother will be considered in relation to the way in which non-

compliant patients are understood by the practitioners. In order to do this, a brief description of Isabella's time in the clinic will be provided below. This description has been extrapolated from my field notes. Isabella was often the topic of conversation during meetings between practitioners and she allowed me to observe her consultations with Sophia, although I never interviewed her.

Isabella was in her twenties and of black British Caribbean descent. She had been diagnosed several years ago and received her HIV care at the DOSH. The practitioners described her as being a "long term non-progressor"<sup>95</sup> and had never needed to take ARVs. Isabella had her first appointment with the antenatal clinic when she was fifteen weeks pregnant. The practitioners expressed concerns about her during their morning meeting on the day she was expected to attend clinic. There were three issues that caused them unease: first Isabella had strong religious beliefs, secondly she had expressed a desire to breastfeed, and finally, she had a child that had been conceived through rape (Field Notes, 30 July, 2008). This worried the practitioners as they felt that patients with this *sort* of history and intention often foreshadowed their resistance to the practitioners' care, specifically as it pertained to medical interventions.

The practitioners came to this conclusion by comparing Isabella's information to their perception of similar cases, either medically, socially or both.<sup>96</sup> This process is a standard procedure in the antenatal clinic. The points of similarity are then used in the clinic as a shorthand description of the kind of patient they feel they are contending with. Such shorthands or motifs could, for instance, be "Pentecostal Christian", "believes in the power of prayer", "West

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<sup>95</sup> The term refers to HIV-positive patients whose HIV does not significantly multiply even when the HIV-positive person in question remains treatment naive — meaning that they do not take ART (Kumar, 2013).

<sup>96</sup> When first meeting a new patient the practitioners would try and establish her religious beliefs in order to assess whether or not they might interfere with the practitioners' care plan. For example, some patients said that taking ARVs would show a lack of faith in God's ability to heal them.

African” or “gave birth to a baby conceived through rape” and serve to alert the practitioners to problems they feel other patients in the same category generally have. However, it is important to note that the practitioners are well aware that a patient’s religious belief may also help her come to terms with her diagnosis (Anderson and Doyal, 2004, p. 95; Tariq, 2013). The motifs help to reveal the practitioners’ perception of the patient’s positionality outside of the clinic and how they consider it may potentially affect her behavior within it. Of particular concern to the practitioners is whether or not they believe the patient will take her medication without resistance and actively participate in consultations. Several of the practitioners told me that adherence to a treatment plan is less likely if the patient exhibits difficulty in coming to terms with her diagnosis and in coping with her life outside of the clinic.

The progression and outcome of a patient’s virus and pregnancy are thus directly related to her acclimatisation to HIV antenatal care, according to the practitioners. Consequently, the practitioners believe that their patient’s course through the clinic can in some ways be discerned and its vicissitudes predicted by observing her present time behavior. They then utilise their judgments of these observations in conjunction with the HIV biomedical technologies available to them. This way of combining data gathered from medical technologies and the use of the practitioners’ interpretation of the patient’s behavior (as a tool to compensate for the perceived insufficiencies of the biomedical and HIV detection technologies available to them) was a highly sophisticated mode of operation in the clinic. The mode of operation subsequently participates in the “production” of the clinic’s HIV patients, as well as modes of intervention and care and their corresponding effects on and in their bodies. Furthermore, the apparent success of the practitioners’ mode of operation affirmed their approach and reifies all of their assumptions and ways of being, their objectivity, their existence and the validity of their interpretations, abstractions and presumptions.

During the following weeks it became clear that the practitioners’ initial concerns were justified. Isabella told them when she was twenty weeks pregnant that she did not want to take any medication and that she wanted to

have a vaginal delivery. Isabella explained during a consultation that she could not understand how her baby could become infected with HIV. She wondered if she had the right to decide if she was to be medicated and to choose the mode of delivery. Sophia calmly explained to her the danger involved in not taking medication and having a vaginal birth. It is important to point out that the practitioners support a patient's desire to have a vaginal delivery under most circumstances, assuming that the patient is on treatment and that her viral load results indicate that this would be a safe mode of delivery (de Ruiter et al., 2014, p. 67). Returning to the patient's case, Sophia advised Isabella to consult with her family who were all aware of her status and to take a couple of weeks to think about the care on offer.

Sophia asked [Isabella] why she doesn't want to take [ARVs]. Isabella said that she just has a feeling that the baby is going to be OK and everything will be OK and she just doesn't want to do it.

Sophia said that she did not want to negate her feelings and that she is all for supporting people and their feelings about their pregnancies *but* this is the information they had to go on. They started to throw percentages back and forth. Isabella had been healthy for a long time and had never gone on medication for her own sake; she was concerned that if she took something during pregnancy she would become sick. She kept on saying that Sophia couldn't guarantee her that that won't happen. Sophia said that she couldn't guarantee her that she wouldn't get sick but that if she didn't take medication, it is such and such a percent risk that the baby would become positive. Isabella said that she had just been able to get around the fact that she wouldn't be able to breastfeed and that that had been very, very hard for her. Now she felt that it was yet another thing that she might not be able to have a vaginal delivery and she might have to take medication (Field Notes, 3 September, 2008, pp. 18-19).

This was, up until that point, one of the most difficult consultations that I had sat in on. I felt uncomfortable and nervous throughout. Isabella expressed

such disdain and suspicion of the way in which the practitioners wanted to medicate her. Moreover, Isabella and Sophia both came across as genuine in their belief that their conflicting plans for Isabella's unborn baby were the most appropriate. Isabella would take the statistical data that Sophia presented and interpret it differently from the way Sophia apparently intended it to be understood. Isabella argued that, based on the data Sophia provided her with, the risks involved with her taking medication and having a caesarean section did not outweigh the potential benefits of surgery and medication. After the patient left, Sophia told me that the practitioners had four weeks to convince Isabella to take medication, as they would want her to start at twenty-four weeks. She said that she had also been nervous and was worried about the way she had answered Isabella's questions. It can be argued that Isabella was making informed decisions about her unborn baby's health as well as her own. However, in this instance, Isabella's behaviour was incompatible with Sophia's plan for care.

A few weeks later, Ellen told Sophia and me that Isabella had phoned in and said that she had decided that she would definitely not take any medication during her pregnancy. Ellen told her that it was the single most important thing she could do. Isabella had asked lots of questions about taking medication. Ellen assured her that it was OK to have questions, but that they needed to end at some point and she needed to start taking ARVs (Field Notes, 17 September, 2008, p. 31).

The way the practitioners dealt with Isabella's desire to "choose" and inform herself of the options ostensibly available to her is indicative of the problems with a logic of choice, as has been defined by Annemarie Mol (2008). In this sense patient choice does not fit with the intricacies of HIV and pregnancy, at least not the way they are understood and dealt with by the practitioners in the clinic. Another related complication is that in Mol's rendition of both the logic of care and the logic of choice, the patient that is cared for is assumed by default to believe that she is in need of the care on offer. Isabella's response to care complicates this assumption. While it could be argued that she was

accepting of antenatal care, she was undoubtedly resistant to antenatal HIV care.

While this way of caring for patients may appear paternalistic, this mode of operation is understood of as being necessary in the clinic. This is because, as mentioned previously, care efforts are directed towards the patient and her unborn babies' future potential. So, if the practitioners begin to view the "present-time" patient's behaviour as being potentially harmful to the patient and her babies' future selves the practitioners *must* attempt to intervene. Ellen articulates these sentiments during our second interview:

Although they're foetuses and they're growing it's a baby to be, and that there's two lives that we're thinking about here, *all the time*, which is why, when a woman is perhaps in denial, or refusing treatment for whatever reason, I can't let that go because we have another life on board that we know we can 99% prevent transmission to that baby, and that child is going to live with the consequences of this decision at this point. *You can't let that go*, you have to keep working at it, you try other means, you can try and reach some sort of compromise about that baby. Obviously our emphasis is [the pregnant patient] and that's how it's seen in maternity, that the baby has no rights until the baby is born, but that's kind of difficult as well, isn't it? Because obviously baby does have rights. I'm still feeling about baby in utero that it's growing and expanding and people who have early miscarriages often view those babies as a *baby* in its own right and it was *not nothing*, you know, it was very important, significant (Second interview with Ellen, the HIV specialist midwife, 18 March, 2009, pp. 12-13).

Isabella's case as I have described it here offers an empirical example of an argument I made in Chapter Two. Namely, that the patients in the specialist HIV antenatal clinic are presented with choices in regards to their care only if the practitioners imagine that all of the possible outcomes of those choices do not pose a significant risk to the patient and her babies' future potential. Accordingly, patients in the clinic are only cared for as if they were autonomous individuals able to make informed decisions about their care if

their decisions appear to conform with the practitioners' plan for care. If they do not, then the practitioners will take it upon themselves to try and ensure the patient's future potential despite her present-time resistance. Here it is important to stress that I am not suggesting that the practitioners *force* their patients to *behave*. Rather, I argue that the practitioners put tremendous effort into persuading patients to want to (or at least act as if they want to) behave.<sup>97</sup> In other words, the pregnant HIV-positive mother is persuasively encouraged to accept certain interventions on behalf of the future health of herself and her future baby, as they have the potential to become postnatally. Patients who resist care are understood as not being able (for whatever reason) to have *faith* in the practitioners and *their* biomedical technologies' ability to enact this vision of a future for mother and baby that is less affected by HIV.

As such, the practitioners were in a position, as illustrated by Isabella's case, where they have to *camouflage* the logic of care that informs their practice to make it look as if it is a "logic of choice", when in fact all of the tenets that inform a logic of choice are fundamentally in opposition to the way practitioners deal with the intricacies of HIV and pregnancy. Thus, Isabella's case illustrates the problematic nature of "choice" as a concept in the clinic. Accordingly, a logic of choice is not a viable option for the practitioners because the pregnant patient is not the *only* patient-chooser that the practitioners take into consideration. This is because the practitioners' concern for the postnatal mother and the unborn baby's future health made a logic of choice an impossibility within their clinic.

Returning to Isabella's time in the clinic, it became clear to me that the practitioners suspected she might not think that she was in need of HIV care at all (Field Notes, 8 October, 2008, pp. 7-9,10-11,13). Ellen said during clinic one day that she thought Isabella might have "issues with her thinking" and that the kind of behaviour she displayed usually had to do with fear or denial (Field Notes, 8 October, 2008, pp. 7-9,10-11,13). Ellen explained that it must be hard for Isabella, as the HIV team had always told her that she was "well"

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<sup>97</sup> The next chapter will further expand on the way the practitioners care for their patients.

and “healthy” (Field Notes, 8 October, 2008, pp. 7-9,10-11,13). She suggested that Isabella’s resistance might stem from a fear of taking toxic drugs during pregnancy (Field Notes, 8 October, 2008, pp. 7-9,10-11,13). Sophia expressed similar sentiments. She told me during clinic that because she suspected that Isabella might not think she has HIV, Sophia could not “use the baby as motivation” to take ARVs, which is what she would normally do in a similar situation (Field Notes, 1 October, 2008, pp. 26-27). Hence, it can be seen that Isabella has to negotiate divergent bits of information which she has received from the health services. One is that she must take medication during pregnancy for the sake of her baby, and the other is that it is dangerous to take toxic drugs during pregnancy. Moreover, she must come to terms with the fact that while she was considered to be “well and healthy” before she became pregnant and subsequently did not ever need to take medication, the presence of an unborn baby in her body has suddenly made her body *risky* and in need of toxic drugs<sup>98</sup> to control it. How to reconcile these conflicting statements? The practitioners are well aware of the problematic I have described above as is evident from the interview extract below:

When they’re pregnant, you’ve got a very short space of time to give a result and then expect them to take on board all this treatment, which could involve toxic drugs, possibly caesareans, medications to baby, bottle feeding — all of that is the opposite of what you’re wanting when people are pregnant. You’re saying don’t take medicines, breast is best, you know, normal and natural and that’s what they want mostly from their cultures and it’s quite an adjustment and it’s a short time span so we have to work with where we are at (Second interview with Ellen, the HIV specialist midwife, 18 March 2009, p. 17).

Here it can be seen that, while it is the crucial work of the practitioners to convince the patient to adopt their strategies for fighting the virus, they allow, nonetheless, for the patient to have a very different understanding of HIV and medicine as long as these understandings do not interfere with the patient’s

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<sup>98</sup> Indeed medically sanctioned treatment breaks have been associated with increased morbidity and mortality (French et al., 2014).

adherence to the treatment plan. Although the virus exists within the patient's body, the practitioners would normally use a language of collusion in which they imply that they are in league with the patient. However, a complete refusal to comply, as well as potentially being in denial of her HIV status, made it impossible for the practitioners to get Isabella *on their side* with them against the virus.

As Isabella's resistance persisted, the practitioners started to talk about being more assertive in their approach. However, the prevailing attitude amongst the practitioners was a desire to "work with her". In this regard, they wanted to avoid mentioning that her baby would have a legal right to care once it was born, and that if she refused, the matter would become a child protection issue after the baby's birth.

Isabella's appointment was very difficult [...] Sophia asked her if she had thought more about [taking medication]. Isabella was completely refusing Sophia would ask: "if you don't want to talk about that, that's fine, explain to me instead, how do you feel about a C-section?" The possibility would be explored and Sophia would say something like "you have to have an epidural", and Isabella would say "*no, I am not okay with that, I will not do this!*" Once Isabella asked what the blood of a person taking [ARVs] looks like Sophia answered that it looks exactly like the blood of a person who is not on [ARVs]. I get this feeling that they are not fully understanding what Isabella thinks of HIV and that is a huge problem, but Sophia drew pictures on a piece of scrap paper of blood and medicine; she drew a round circle and she described what the medicine would do and Isabella seemed really interested and she would say "*now I understand, so this is what the medicine does, this is really interesting*", and then Sophia said "are you ok with this"? Isabella responded "this is really interesting, but I am *not going to take it*" (Field Notes, 8 October 2008, pp. 10-11)!

The practitioners were even more concerned during clinic the next week. Isabella had told them that she did not want the baby to be given any postnatal medication. The practitioners spoke more about getting a child protection order placed on the baby once it was born (Field Notes, 22 October, 2008, p. 3). The following week Ellen told Sophia and me that she had heard from a midwife at another hospital that Isabella had registered as a new patient with them. Isabella did not disclose her HIV status to the hospital. Furthermore, she told the hospital's antenatal practitioners that she did not want the team at London Hospital to know that she had "moved hospital".<sup>99</sup>

Marie [a consultant physician in the clinic] said that [Isabella] believes that her child is going to be negative and according to statistics, the chances are greater of her child being negative, even without her taking treatment, than are the chances of the child being positive. If she does end up having a negative baby and takes treatment she is going to think that it had nothing to do with treatment and that it was her God that protected her; if she does not take treatment and has a negative baby then she will think the same. Either way, her belief system is not going to be interfered with or changed and her belief system in and of itself would not necessarily make her a bad mother.

Marie did not say this in a way that made me believe that she felt that she had to convince the others of this. It was more like she was trying to sort it out for herself, as if she needs to have a way of reconciling the idea of a good mother with a mother that does not take her pills nor wants her baby to have triple therapy (Field Notes, 5 November, 2008, pp. 10-11).

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<sup>99</sup> Isabella informed her new midwife that she had been Ellen's patient at London Hospital. Isabella's new midwife contacted Ellen in order to organise the transfer of Isabella's antenatal notes. This is standard practice if and when a pregnant patient moves hospital. However, Ellen had a professional relationship with the antenatal team at Isabella's new hospital. Consequently, everyone in the new team knew that Ellen only cared for HIV-positive women. Thus, Isabella inadvertently disclosed her HIV status to her new care providers by revealing the name of her previous midwife. It is important to add that Ellen's professional title (HIV specialist midwife) would have alerted Isabella's new midwife to the fact that Isabella was HIV-positive, even if the new midwife had not known Ellen professionally. Ellen's well-known presence within the NHS in London reflects the discussion in Chapter Three that considers the difficulties I have in ensuring the anonymity of the practitioners mentioned in this study.

What is particularly important about Marie's observation is that it alludes to parallel logics and she recognises the generative effects of HIV interventions. Thus, available data and the patient's "care outcome" would be used to confirm the validity of any particular rendition of HIV, although it is important to note that I do not think that Marie would view Isabella's apparent understanding of HIV as having the same validity as her own. Furthermore, the extract illustrates that Marie does not think that Isabella's behaviour necessarily makes her a "bad mother" (in this instance meaning someone who makes careless and random decisions about her baby's health). It is important to note that none of the patients mentioned in the clinic were ever consistently constructed as being bad mothers. Rather, the practitioners spent a significant amount of time and energy trying to make sense of behaviour that was suspect in a way that still allowed the patient to be and or have the potential to become a "good mother". In relation to this, I argue that contained within the promise of a future less affected by HIV for mother and baby, is, from the practitioner's perspective, the present-time patient's (who displays questionable maternal behaviour) final transformation into a good mother. In other words, the practitioners allow for the possibility that problematic behaviour displayed by present-time patients may dissipate in the future if the practitioners are able to successfully secure mothers' and babies' imagined potential.

Moreover, I argue that the practitioners' ability to envisage all patients having the capacity to become good mothers is vital to the provision of care in the clinic. This is because the practitioner's ability and desire to provide the calibre of care that they feel their patients need requires that the practitioners *care* about their patients. In other words, the practitioners feel that successful care requires that they offer their patients the possibility to partake in an emotive and genuinely caring exchange with them. This kind of relationship would be more difficult for the practitioners to establish and maintain if the patient was reprehensible in the way a "bad mother" would be. This is significant and will be considered in more detail in Chapter Five wherein I further discuss the care the practitioners provide.

Returning to Isabella's story, Ellen let us know a few weeks later that a meeting had been held concerning Isabella at her new hospital. Isabella had told the team that she wanted to breastfeed her baby. Ellen explained to us the different possibilities of what would happen to the baby once it was born. One option would be that Isabella would be asked to come into hospital and be supervised while giving the baby medication; another possibility would be to place the baby in temporary foster care during the time it needed to be medicated. Ellen said that this might be necessary, as they could not rely on Isabella to give the baby its medication voluntarily. Marie wondered why they would not automatically take the baby into care, as Isabella was insisting on breastfeeding. Ellen explained that a court case had decided that the "law could not stop a mother from breastfeeding", therefore placing the baby in care on the sole basis that an HIV-positive mother was going to breastfeed was not an option (Field Notes, 26 November, 2008, pp. 9-11).<sup>100</sup> Ellen told us about a midwife at yet another hospital who had several babies that were HIV-negative. Ellen said they had had three tests done after they were born so they were definitely negative, but then the mothers breastfed them and they became positive (Field Notes, 26 November, 2008, pp. 9-11).

During clinic the following week, Ellen relayed a phone conversation she had had with Isabella. Isabella had explained to Ellen that she has to "trust in God", that everything will be fine and that bottle-feeding would show a lack of faith (Field Notes, 10 December, 2008, p. 2). Ellen had attended a child protection meeting at Isabella's new hospital, during which a child protection plan had been devised. The plan was as follows: Isabella would have to stay in the maternity unit for five days, the baby would be put under a police protection order if she left. The hospital's specialist midwife would be on call until the baby was born as Isabella had threatened to have an (unapproved) home birth. Isabella turned up at the hospital on the day of the meeting and agreed to take medication immediately, have a caesarean section and to replacement feed. However, she called the next day and said that she had changed her mind (Field Notes, 7 January, 2009, pp. 7-8).

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<sup>100</sup> This stance is supported under article 8 in the European Convention on Human Rights (ECHR). The ECHR became part of UK Law through the Human Rights Act 1998 (BHIVA, CHIVA and BASHH, 2009, p. 10).

We found out that Isabella gave birth a few weeks later at the other hospital and had agreed to allow her baby to be medicated. Ellen said she was really a very complicated woman who had pushed all the boundaries (Field Notes, 21 January, 2009, pp. 3-4). Sophia spoke to Isabella who told her that she now feels she should have listened to the practitioners at the London Hospital in the first place because the only result of her having gone to a different hospital is that more people know that she is HIV-positive, which is what she did not want. Ellen told me during our last interview that Isabella had left the country; this was the last I ever heard of her. Consequently, I do not know if vertical transmission of HIV was prevented or if she ever returned to London Hospital for her own HIV care. The issues I would like to draw out from Isabella's time in the clinic are the expectations placed on patients regarding their provided care. Thus, the patient's autonomy and consequently the patient's ability to choose are superseded if and when a present-time patient's behaviour may interfere with her and her babies' future potential.

Therefore, Isabella's case makes clear that when making decisions about the patients' care in the present, practically speaking the requirements of HIV and pregnancy (as perceived by the practitioners) necessitate that they consider the feelings they think their patients and (potential) offspring may have in the future. This is particularly significant because it alludes to some of the complexities that may occur in the specialist clinic if a pregnant patient resists or refuses the practitioners' desired care plan. Consequently, practitioners in an HIV specialist antenatal clinic would base their care decisions on the patient as she is now *and* on what they hope she and her baby will become in the future. In a more abstract sense, they are consulting with a real present time patient, with her future self, and with her future baby as the practitioner imagines them to have the potential to become if care is successful. Imagining and thus considering the future in this way is an important aspect of the care that the practitioners attempt to provide their patients.

## Conclusion

This chapter explored what Mol would refer to as the practitioner's logic as it was embedded in their practices (2008, p. 8). I have reflected on how the identity of HIV within the antenatal clinic depends on the practitioners' continued and sustained maintenance (Mol, 2002, p. 23). Furthermore, I have explored how practitioners in the clinic viewed various actors' (that are part of care in the clinic) ability to obstruct the practitioners' desired care outcomes. Moreover, this chapter considered how the logic of care in the clinic required that the practitioners anticipate the way the patient's body, virus and unborn baby will develop antenatally, in addition to constantly anticipating and working towards a specific future for both mother and baby. Also, I have illustrated how the practitioners constantly anticipate threats to the process that would enable mother and baby to fulfil their potential. These threats can come from any and all directions: the patients and the technologies that the practitioners depend on to inform their practice. In relation to this, I considered how the future patient always had the potential to be a good mother and that the practitioners see themselves as having the ability to help a mother become good in the future — if their care was successful.

Additionally, I have explored the particulars of the way HIV interventions are dealt with in the clinic. I have considered how the healthcare professionals understand these interventions and how they believe their patients may contend with them. Moreover, I have illustrated how the healthcare practitioners have ways of contending with patients whose behaviour is understood as possibly threatening their future potential.

The chapter considered the significance of the patient's diasporic positionality as it related to some of the assessment technologies the clinic depended on. I argued that the successful prevention of vertical transmission of HIV in the clinic was related to the work practitioners do, and that this work was informed by the specificities of the logic of care in the clinic. Thus, the successful prevention of HIV as I described it depends on all the practitioners within the clinic working towards the same goal and being able to anticipate and

compensate for any disruptions. However, according to the practitioners in the clinic, issues related to their patients' diasporic positionalities may complicate the care practitioners would like to provide.

Moreover, throughout this chapter it has been made clear that the care practitioners provide their patients with is concerned with and involves both medical health expertise and biomedical technologies as well as encompassing the patients' and her offsprings' imagined potential. This chapter has begun to consider what this care attempts to achieve, what it entails, and what it requires of both practitioners and patient, from the practitioners' perspective. It will become clear throughout the remaining empirical chapters that this form of care is imagined by the practitioners as having the potential to encompass their patients, as well as everyone that is and may become connected to their patients (as they are now and as they may become in the future).

From the practitioners' perspective, the provision of good care which is synonymous with caring care depends on their ability to compensate for any potentially harmful technologies.<sup>101</sup> In other words, the successful provision of care in the clinic requires, according to the practitioners, a system that is able to substitute and, when needed, counteract, any or all of the biomedical technologies that do not *do* (or are suspected of not doing) HIV in a particular way. Subsequently, the prevention of vertical transmission of HIV concerns the particular care on offer, the attributes of the people who provide that care, and the way in which the biomedical technologies available to them are anticipated, interpreted and incorporated into the lives and bodies of their patients.

Therefore, from the practitioners' perspective, the unquestionable success of their clinic in preventing vertical transmission is related to their constant sense of unease, which in turn, motivated them to actively seek out certain knowledges of their patients' bodies. This requires complex and rigorous

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<sup>101</sup> For example, viral load assays.

negotiations with all of the various components within the clinic (and external to it), and is informed by the emotive approach to care that permeates and influences the practitioners' practice.

Providing good care thus requires that the practitioners make themselves available to have an emotive connection with their patients. Importantly here is the idea that the practitioners try to make it clear that they care, and that by caring they hope that they are able to make up for the shortcomings of the technologies on offer to them. The next chapter will further consider the way the practitioners told me they feel about the care they provide and the significance of the HIV diaspora.

## Chapter Five: Providing Care within the HIV Diaspora

It shouldn't be that if you're in the developed world you're fine but if you're in Ghana, you're not fine [...] [B]eing an asylum seeker now is just, you know [...] I don't know how my patients survive (First interview with Sophia, the HIV specialist doctor, 30 September 2008, p. 14).

This chapter will explore what constitutes *good care* from the practitioners' perspective. I will do this by providing examples of things the practitioners believed had the potential to entirely disrupt what I will term the *network of care*. This chapter argues that issues related to the patients' incorporation within the HIV diaspora pose a constant threat to the provision of care in the clinic from the health care practitioners' perspective. Drawing on field notes, interviews with practitioners and an interview with a patient, I will explore several different areas of concern where the network was jeopardised. By exploring the events and circumstances that threaten clinical practice, this chapter will further investigate how the practitioners contend that the identity of HIV is maintained and how the prevention of vertical transmission of HIV is done in the clinic. Through this analysis I will consider the significance of the practitioners' attempts to achieve their patients' potential.

The chapter will begin by considering Marilyn Strathern's article "Cutting the Network" (1996). This discussion will clarify what I mean by a network and what the network may enable if it is not cut. The rest of the chapter will then describe instances when the network was either threatened or cut. Accordingly, I will consider how the practitioners conceive of and negotiate the possibility that the patient's unspoken feelings about HIV may impede and complicate their ability to help secure the patient and her babies' ultimate future selves. I will contemplate how the practitioners try to prevent certain events from taking place — events that the practitioners fear would be counterproductive to the future wellbeing of their patients and their offspring — if and when these events would become enacted. This discussion will

clarify the work that the practitioners do in the present in order to influence their patients (as the practitioners imagine them) in the future. Moreover, I will argue that the patient's imagination becomes viewed as a result of the effects of their location within the HIV diaspora.

In the clinic, a compromised relationship between practitioner and patient, regardless of what caused the conflict, is one of the most detrimental potential obstructions to the provision of care. In other words, I will argue that the provision of care is, from the perspective of the practitioners, entirely dependent on developing and maintaining certain kinds of relationships with their patients. At its best, the relationship should entice patients to have *faith* in the practitioners' desire and ability to *care for them*. The analysis of the practitioners' practices and of the issues and events that they feel are a potential threat to their practices will help me to uncover the *logic of care*, that is the rationality of the practice in which they engage (Mol, 2008, p. 8). The chapter will then consider the ways in which issues that stem from the patient's immigration status may harmfully impact on the care that the practitioners would like to provide them with. After this, the chapter will discuss the threat that patients' (suspected) past traumatic experiences may have on the network of care. Finally, I will consider an instance where the practitioners felt that a patient had been provided with bad care.

### **Disrupting the provision of care**

In her influential article, "Cutting the Network", Marilyn Strathern argues that for actor network theorists the concept of a network refers to the "heterogeneous elements that constitute [...] an object or event, or string of circumstances, held together by social interactions" (Strathern, 1996, p. 521). She contends that in order to have analytical power a network must have a stopping point (1996, pp. 522-523). After all, she asserts, there are potentially never-ending amounts of networks within networks; where to draw the line (1996, p. 523)? In regards to this she writes:

a network is as long as its different elements can be enumerated. This presupposes a summation; that is, enumeration coming to rest in an identifiable object (the sum). In coming to rest, the network would be “cut” at a point, “stopped” from further extension. How might that be done (Strathern, 1996, p. 523)?

For Strathern, a network is cut by a disruption: for example, a claim of “ownership” (1996, pp. 525-526, 531) which would separate those who belong in the network from those who do not (1996, p. 525). For example, she mentions that step-children may not appear in grandparents’ wills, drawing a line between those who inherit and those who do not. However, the events that cut or have the potential to cut a network may vary depending on the specificities of the network in question.

Influenced by Strathern, I will use the concept of a network to refer to the conglomeration of components that would work and/or come together and facilitate the patient’s passage through the clinic, and the emergence of the imagined postnatal woman and her (hopefully) HIV-negative baby, as the practitioners envision they have the potential to become (1996, p. 520). The network that may enable this outcome is held together by and through the relations between the various actors within it (1996, p. 521). The provision of care requires that the network that facilitates care is not cut, as Strathern (1996) uses the term. Drawing on these ideas, in what follows I will illustrate how the practitioners believe that patients’ (beliefs about their) *future expectations* may have the potential to cut the network of care.

### **Patients fears for the future, preventing an imagined future**

In this section I will consider the way in which practitioners manage a patient’s fears for her future. As I have discussed previously, the work the practitioners do in imagining a future for their patients, i.e. a future less affected by HIV, is fundamental to the care they provide in the clinic. However, I will show how the practitioners fear that their diasporic patients may disrupt their own care if the patients engage too deeply in the work of the imagination. In other words,

from the practitioners' perspective, *imagining a future* for the patient is vital to the prevention of vertical transmission and their provision of postnatal care. But it is potentially detrimental to prevention and care efforts if their patients imagine it differently. In other words, patients must, according to the requirements of care, be encouraged to imagine their future but only as the practitioners would like them to. Thus, the practitioners believe that a patient who is too preoccupied with her and her baby's future paradoxically risks cutting the network of care that would prevent vertical transmission and any forthcoming care. In what follows I will provide examples of how the practitioners encourage their patients not to think too deeply about the effects the HIV diaspora may have on their lives.

The work that the health care providers do is partially about trying to get patients to not *give in* to the future possibilities that are in store for them. At the same time, the practitioners' work in the present is always informed by the future imagined possibilities for the patient and her potentially HIV-negative baby. The practitioners are able to provide a significant amount of reassurance to their patients about their prospects in the present and near future. Accordingly, the practitioners are able to more or less guarantee that their patients will have HIV negative babies if the patients adhere to their care plans. In other words, patients must engage in care appropriately according to the practitioners (Gardner et al., 2011, p. 793). Beyond that, however, the practitioners are not able to give any assurances about their patient's life prospects if the patient's ability to stay in the UK is under question. To illustrate this argument I will describe my observation of a consultation between Yaema and Sophia. Although I never interviewed her, Yaema consented to my attendance at all of her consultations.

Sophia was comforting a very upset patient. Yaema<sup>102</sup> was having her final postnatal appointment and she was considered to be well and healthy and her baby, who was just over six weeks old, had recently received an HIV-negative

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<sup>102</sup> Yaema was originally from Sierra Leone.

test result.<sup>103</sup> During the consultation, Yaema broke down in tears. After some cajoling Sophia was able to establish that Yaema thought she would fall down dead at any moment. Sophia comforted Yaema in the following way:

[Sophia said that] if they were having this conversation in Ghana<sup>104</sup> then things would be very different because there are not the same medicines there. Sophia explained that if she spoke to a patient in Ghana and the patient said that they were afraid to die, she would say: “yes I understand that and I will do what I can for you now”. [But] because they were in the UK and they have all these medicines, she could tell the patient that you might be afraid of dying but that is not going to happen — “there is no reason why you and I should have a different life span” (Field notes, 24 Sept, 2008, p. 21).

Later, I asked Sophia to expand on the analogy she had given Yaema:

Ulla: With one of the patients you were speaking, when you spoke to her about HIV you were setting up location specific scenarios. You were saying, “in Ghana I would say this, and here I would say this”, how important do you think a patient’s previous experiences from a different location of HIV is to their understanding?

Sophia: Oh, I think it’s immense because, I think that, your AIDS defining illnesses are you know, when I see someone with full AIDS defining illnesses, where you have got stigmata in your face, your mouth, your skin, everywhere; you’re emaciated; you know those are very harsh pictures to remember and then [...] particularly, if you knew them pre-HIV/AIDS, you would think “oh my goodness they were just like me and that’s how I’m going to end up, so just because I’m not like that now that’s how I could end up”! [...] you can either be focused and say I will never let myself get to that point and I’m going to do everything I can, and I’m going to work with the doctors or whatever, or you can become

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<sup>103</sup> Please see Chapter One for a discussion of the neonatal management of babies born to HIV-positive mothers.

<sup>104</sup> Sophia had worked as an HIV doctor in Ghana and would often use Ghana as a point of reference when discussing HIV care in Africa with patients.

apathetic and think that's my destiny and what else am I going to do, and go on from there. And that's a very simplistic view but it's I think, I'm just trying to highlight the fact that it can really impact on where you go next and how you engage in services next. I think it's the fear factor [...] I think it's important to say, "look, it's there, but we can manage it and if we were in a different setting, your fears would be justifiable and so I'm not dismissing your fear but I am saying that we've got something different that we can offer, so that will not be inevitable", and then, I think it's quite a nice analogy for them (First interview with Sophia, the HIV specialist doctor, 30 September, 2008, p. 11-12).

Sophia's comment draws attention to the fact that the patient's valid fear about the future may get in the way of her engaging in care in the present. In other words, while she may only have temporary access to biomedicines and care, fully benefiting from them while she does have access might be curtailed because she knows that her access is temporary. Consequently, the patient must be persuaded to think about her future prospects in a way that the practitioners believe is conducive to her care in the present. The practitioners know that their HIV diasporic patients, who are at a high risk of being removed from the UK, are probably realistic in questioning an imagined future "less affected by HIV". So, there is a contradiction in this process: namely, that care depends on the practitioners encouraging patients away from thinking about futures the practitioners know are highly probable.

Returning to Yaema's consultation, Yaema seemed comforted by Sophia's reassurance. However, underlying Sophia's discussion about a patient's life prospects depending on her geographical location was the fact that Yaema was living in the UK illegally. So, while Sophia was offering Yaema reassurance that her life was not in danger now, she was simultaneously acknowledging that Yaemas' life *would* be in danger in the future. Important though is the fact that Yaema's possible expulsion from the UK is an event that would take place (if it ever does) in the distant future. Thus, I would argue that Sophia was trying to encourage Yaema to take advantage of the life that is available to her *now*. In other words, Sophia was trying to persuade Yaema

from allowing her likely distant future to impede Yaema from benefiting from the care and biomedical technologies available to her in the present and in the near future. Care in the clinic is thus directed towards the *near* future patient — a future that does not extend beyond their access to care and biomedicines. That is, the successful provision of care requires that the patient works towards the practitioner’s vision of the near future, while the patient simultaneously refrains from imagining a potential but distant one. Put another way, the care that the practitioners provide depends on the patients not “cutting the network” that provides care, as a result of thinking too much and too negatively about their future prospects.

Following this, I argue that for the practitioners, imagination (their own and their patients’) is an activity that becomes part of the *real* of HIV. Influencing the content and expanse of the imagination is therefore crucial. This reflects Rosengartens’ comment that: “imagination — as a mode of thought contrary to the presumptions of objective knowledge — is always present and inherent to what we take to be an external, unmediated ‘real’” (2009, p. 21). It is important to emphasise that, especially from the practitioner’s perspective, the fact that the imagination has this influence over what HIV may become does not in any way demote the status of “objective knowledge” about it. In other words, from their perspective, the imagination (their own and their patients) has a critical part to play in creating the HIV that is in a patient’s body (but cannot be known in real-time), but the HIV is nonetheless an “external, unmediated ‘real’” (2009, p. 21).

Here I will make another argument in relation to the same empirical example. I contend that the practitioners use their ability to *work with and within sadness* as a tool that helps them direct the way their patients contend with their feelings and curtail their future imaginings. The following is an extract from my field notes which describes how Sophia and I interacted with Yaema and her baby during the consultation.

Sophia and I started to focus our attention on the baby, admiring her and talking about how lovely she was and how we couldn't believe that she cried all night. Yaema said that her baby was [HIV-] negative, as she held her. Sophia said, "yes, see she is ok, she is beautiful, and she is lovely, you have to live for her and you will live for her and everything will be ok". [...] It was really sad. I felt an overwhelming desire to reassure [Yaema], comfort her — almost a physical reaction where you want to physically care for someone, and help them, but without being able to do that.

Sophia wanted to examine [Yaema's] chest. Yaema was holding her baby; she gestured towards me and I asked if I could hold the baby. Yaema looked happy and gave her to me. The baby was absolutely gorgeous. I think it meant a lot to her, the way that both Sophia and I admired her baby; I think that made Yaema feel more comfortable. Sophia reiterated that this is normal; a new mother doesn't sleep and she has feelings of anxiety and being tired. I think she was attempting to normalise her experiences, to take them away from HIV and relate them to the experience of being a mother [...] I felt very close to Yaema and I felt close to Sophia during the meeting. [The consultation] was very exhausting and I had to focus on not crying; I could tell that Sophia was as well. It was hard to see someone that upset (Field notes, 24 Sept, 2008, p. 21-22).

There is something very important (albeit subtle) that I would like to draw out of the extract above. My overwhelming emotion during the consultation was a desire to physically comfort Yaema, and because I felt that was not appropriate, I projected my need to comfort her onto her baby. Sophia, however, did not allow the emotionality of the consultation to stop her from providing Yaema with specialist HIV care. By this I mean that Sophia cleverly — and taking cues from Yaema herself — attempted to get Yaema to see the benefits of her current situation by directing the conversation towards her baby, and reiterating how it was born free of HIV, how beautiful it was and how normal it was to feel overwhelmed and sad when you are a new mother.

This way of negotiating Yaema's sadness was not, I argue, a kneejerk response to someone crying; instead it was a crucial component of the care the practitioners provide their patients. Accordingly, providing care to patients located within the HIV diaspora requires that the practitioners are able to maintain the provision of care even when things are desperately sad and the patients' future is bleak. Further to this, the provision of care requires that the practitioners use those sad moments as opportunities to direct the way their patients think about their lives and their futures. Consequently, incidents when patients opened up in this way were approached by the practitioners as tremendously advantageous opportunities in the clinic. The practitioners could, if they managed these situations appropriately, ensure that the patients felt cared for, able to articulate their fears and begin to think about their (near) futures differently.

Potentially emotive situations are used as opportunities for the practitioners to convey their desire and ability to provide caring care (i.e. the provision of good care in practice) to their patients. Practitioners would even create such emotion. They would draw out key moments in the patient's pregnancy and attempt to instigate an emotive discussion with the patient about it. For example, they would encourage patients to talk about the purchases they had made for their unborn baby, the unborn babies' possible names, and the way it felt when the unborn baby moved inside of them, and so on. I argue that these discussions had the dual purpose of normalising the patient's pregnancy and also of establishing caring relationships between patient and practitioner. So, I argue that in the specialist clinic any sign of a patient's emotion is used by the practitioners as a possible *point of entry* to allow them to display that they cared about the patients.

The provision of caring care in the clinic depends on the patients feeling cared for. Importantly, this does not mean that the patient needs to believe that the practitioners will be able to prevent vertical transmission of HIV, but rather, that the patient believes that the practitioners care about her and her (unborn) baby, above and beyond HIV. The responsibilities of "caring care" are thus not satisfied once it has been established that a baby has been born free of HIV

and the mother has had her last postnatal appointment. Instead, “caring care” is an ongoing process that concerns the patient’s future potential, and the potential of any babies and sexual partners she may have in the future.

I felt closest to Ellen and Sophia during intense interactions with patients like the one described above. While I would usually feel overwhelmed during these distressing consultations, Sophia’s and Ellen’s professionalism never appeared to weaken in these situations. Thus, I argue that the dilemma I describe in Chapter Three in regards to my concern over possibly attending the caesarean sections would not present itself in the same way for the practitioners in the clinic. Rather, being able to feel deeply, and access, convey and feel an emotive connection with a person in a horribly difficult situation, while not losing sight of your responsibilities as a professional, i.e. your job to provide care, is part of the logic of care in the clinic. Indeed, according to the practitioners, being able to connect with patients on that level is a necessary skill for health care providers within the HIV diaspora.

### **Immigration status**

[M]any of [the patients in the clinic] have issues around just life really. Poverty, immigration status and having an HIV diagnosis where they’re going to need treatment could mean that they have to stay in the UK to get that treatment and to *live*, and therefore they’re restricted in what their future might be (First interview with Ellen, the HIV specialist midwife, 21 Aug 2008, p. 3).

In the previous chapter, I argued that people living with HIV in the same geographical location might not experience the transformative opportunities promised by the availability of the care and technologies elsewhere. This argument was made in relation to the viral load assays used by the specialist clinic. Here, I will extend that argument by showing how the way various professionals interpret and subsequently follow bureaucratic guidelines and laws and “do their jobs” may obstruct the patient’s access to care. This argument will be made in relation to a patient named Verity. I will show how

practitioners connected to the clinic's reactions to her immigration status disrupted her access to care in the clinic. Moreover, I will contend that Verity's case evidences how global inequalities that pertain to unequal access to ARVs and specialist HIV care may be echoed in the clinic.

Verity's situation reflects the geopolitical concerns discussed in relation to Didier Fassin's work in Chapter Two: namely, how people have different things happen to their bodies as a consequence of their varying access to resources. However, it is important to mention that Fassin makes this argument in relation to a global "west and the rest", to use his terminology. Instead, I use his argument to consider the way in which location-specific inequalities may follow diasporic people as they move location. In this way, if we were to impose the empirical example I provide onto Fassin's argument and use his terminology, then the inequalities he writes of *follow* "non-western" peoples as they move to the "west" (2007).

Despite their best efforts, the practitioners are not always able to care for women who come into contact with the clinic in the way they would like to, even if the woman herself acquiesces to and participates in HIV care "appropriately". Failure to actualise their intended care plan in these instances is a result of the way the care provided is necessarily dependent on other actors that may sometimes be antagonistic to the practitioners' concerns. It is these other actors that intercede into care (and may entirely obstruct the provision of care) in the clinic. It is important to stress that these obtrusive actors become involved in the network of care as a direct result of the patient's position within the HIV diaspora. In the example discussed in this section, the patient's immigration status in combination with her complex medical needs made her vulnerable to these actors. Moreover, in some circumstances, the purpose of these actors' roles is precisely to thwart the provision of care to certain groups of people. While the preceding chapter considered the ways in which the provisions of care were complicated because of viral load assays, here this problem will be considered in relation to different empirical material and consequently further clarify the work that the practitioners do when attempting to provide their patients with care.

The following story, as I narrate it below, is taken from several weeks' worth of field notes and an interview with Anne, a consultant physician whom I asked to explain her relations with Verity, the patient in this story. It is important to note that the information that the clinic gained about this patient was gathered over these weeks. In this way, I am providing a streamlined description of Verity's time in the clinic and the conversations the practitioners had about her, whereas in reality the MDT painstakingly gathered much of the information about her over an extended period of time. Here it is significant to add that Verity only attended the specialist clinic on one occasion.<sup>105</sup> Verity and her partner consented to my participation in Verity's consultation. To my knowledge, none of the practitioners asked Verity if I could interview her, and no interview with her took place.

During a briefing meeting in clinic one day, Marie, a consultant physician, told us about a new patient named Verity: she was 13 weeks pregnant and had come to the UK from a country in Sub-Saharan Africa a few months ago. She was on a visitor's visa that was about to expire. Verity became very sick a few weeks back and was admitted to North London Hospital<sup>106</sup> (NL Hospital). They diagnosed her with tuberculosis and discovered that she was pregnant and HIV-positive. She was subsequently transferred to the Central London Hospital (CL Hospital) because NL Hospital does not contend with TB and HIV co-infection (Field Notes, 17 December, 2008, pp. 4-5). During her time there, a doctor told Verity that her immigration status would not entitle her to secondary care<sup>107</sup> which would encompass HIV care according to him. Thus, she would be able to receive tuberculosis therapy and immediate necessary obstetric care, with the bill to be paid at a later date (Interview with Anne, a

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<sup>105</sup> Although I do not expand upon it here, another issue Verity's case brings up is the tremendous amount of time the MDT would spend talking about patients. This becomes particularly noticeable in relation to Verity, considering that she only attended one clinic session. Despite this, her case was discussed in clinic for several months.

<sup>106</sup> I have chosen to provide pseudonyms of two hospitals mentioned in relation to Verity.

<sup>107</sup> Secondary care refers to planned or unplanned emergency care and/or surgery (West Middlesex University Hospital NHS Trust, 2014). HIV antenatal care is considered to be emergency care in the specialist clinic. So, Ellen felt that Verity's HIV care should have been considered emergency care because Verity was pregnant. The care that the practitioners provide in the clinic is planned emergency care due to the combination of HIV and antenatal care. For example, patients have a care plan in place and have scheduled appointments for various procedures. Therefore, emergency care can be planned.

consultant physician, 11 March, 2009, p. 17). They were firm but kind in their rejection of her (Field Notes, 10 December, 2008, p. 3). All of the practitioners expressed their shock and disappointment that Verity had been refused HIV care. Ellen was dismayed and said that her HIV care ought to be considered emergency care because she was pregnant and it was a crisis<sup>108</sup> (Field Notes, 10 December, 2008, p. 3). Verity came to clinic the following week with her partner, Jack, a white British man who had recently been diagnosed with HIV infection. Sophia and I met with them in the consultation room.

The appointment was overwhelming. Verity looked extremely ill, scared and vulnerable, and she was remarkably skinny. Her skin looked lifeless, was an ashy greenish brown, and appeared to hang off her thin frame. Verity's movements were also slow and laborious; her breathing was strained and she appeared to be in great discomfort throughout the consultation. I would never have suspected her of being pregnant. Verity and her partner seemed to be full of anticipation; they sat at the edge of their seats and listened attentively to everything Sophia said. They both asked lots of questions. Jack wanted to know if the clinic would really care for Verity. They appeared to breathe a sigh of relief when Sophia assured them that the MDT would help her. The couple looked noticeably reassured and started to thank Sophia over and over again. Sophia looked visibly touched by their heartfelt gratitude. The entire interaction was tremendously emotional. The following is an excerpt from my field notes:

[Verity and Jack] did not seem angry, or they did not express their anger at this other hospital for refusing them care; they came across as just being grateful, and that almost upset me more. [The London hospital] did not have any information about this woman's HIV, but the woman brought out some letters from the hospital and it turns out that her CD4 count is very low and her viral load is high, and even if she was not pregnant, she should be on treatment for her own safety for her own health. And she has TB and she had pneumonia in 2004, and it hit me

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<sup>108</sup> Free access to HIV care for anyone with HIV living in England, regardless of his or her immigration status became a legal fact in 2012 (Department of Health, 2012; The National Health Service (Charges to Overseas Visitors) Regulations, 2011).

that a doctor turned her away from treatment, knowing full well that that would probably mean that her child would be HIV-positive [and that she might die](Field Notes, 3 December, 2008, p. 9).

Jack was very worried that their baby might have already been infected with HIV since Verity had not received any treatment. Sophia acknowledged his fear and explained that this might unfortunately be the case and that all they could do now was try and prevent the baby from becoming infected, if it had not already been. It is important to reiterate that this couple had spent several weeks desperately trying to find a hospital that would provide Verity with HIV care. They wanted their baby and they wanted it to have the best possible life chances.

Sophia, Ellen and Marie decided that despite the fact that they would ideally want Verity to start taking ARVs as soon as possible they would have to wait until they received her “new results” the following week. The delay was necessary due to the incompatibility of some HIV medications with TB treatments. Another pressing concern was the fact that Verity would receive her care at different hospitals, which would be logistically challenging. Marie wanted Sophia to try and persuade Verity to choose to have both her HIV care and her TB care at the London Hospital because of the tremendous difficulties inherent in caring for both illnesses and her pregnancy (Field Notes, 3 December, 2008, pp. 1-2, 6, 8-11).

I was overwhelmed by a sense of relief after Verity and Jack left — relief that Verity would now be cared for, that I knew all of the practitioners in the clinic would do their utmost to ensure that her baby had the best possible chances of being born free of HIV, and that she would finally receive skilled and compassionate care. I felt she was safe now, as safe as she could be in these circumstances. It is important to stress that I got the impression that the practitioners in the clinic also felt immensely happy that they were going to be able to help Verity and Jack. It was as if they were going to be able to rectify a horrible injustice that was taking place. The consultation felt hugely significant

and the practitioners' dedication and ingenuity was humbling and elevating to witness. I felt proud of them and the work that they were doing.

Ellen updated me on Verity's progress during clinic the next week. Verity and her partner had been given a prescription for ART that would be compatible with her TB therapy. The following is an excerpt from my field notes:

[Verity and Jack] had had a complete nightmare getting [her prescription] out of the pharmacy. They had waited around for hours and then could not get it, and then they had gone to two local community pharmacies that did not have it; and it had just been a long process and both Ellen and Marie were talking about how difficult things were with the pharmacies and how ridiculous communication was with patients. The pharmacy told [Verity and Jack] that they would give them a call as soon as the medication came in, and never called [them] and then Marie called the pharmacy and they actually did have the medicine there to begin with (Field Notes, 10 December, 2008, p. 3).

Verity was discussed in clinic again the following week. Sophia had asked the London Hospital TB doctor if he would be willing to care for Verity; he had refused. It is important to mention that Verity did not reside within the hospital's jurisdiction, meaning that Verity was not entitled to receive her medical care there. Consequently, her care would be split between the London Hospital and NL Hospital. In other words, Verity's complex medical needs and her residency in a particular area of London all conspire to make it impossible for the MDT to care for her.

The practitioners in the clinic often discussed the way in which circumstances directly connected to their patient's position within the HIV diaspora significantly complicated the MDT's ability to provide them with care. These sentiments are reflected in the extract from an interview with Anne, a consultant physician in the clinic.

In this particular part of London, we have got a group of patients who are marginalised in every which way. In the early days of the epidemic when

you were dealing with people with a relatively rich constituency of British born men, there was a power there and people would listen; we are now dealing with what is a feminised epidemic and women are notoriously not listened to. Of a racial minority who are stigmatised and are marginalised and are not wanted, so it's a discourse about migration, which is unpopular; to say to somebody, I'm looking after undocumented migrants with HIV in a disadvantaged bit of town, can you help? People go, ahem, well, I don't know if we can, actually. So it is to do with where they are situated I think, politically, and being a migrant is a very difficult place because people don't have any ownership for your problems (Interview with Anne, a consultant physician, 11 March, 2009, p. 2).

A further complication that emerged was that Verity was discovered to be resistant to the preferred TB therapy; this irrevocably complicated her HIV care. Sophia said that if Verity had not had a partner who was fighting for her life it would never work (Field Notes, 17 December, 2008, pp. 4-5).

Then they had a huge talk about the "rubbish" pharmacy; everyone was upset; Heather [a MDT paediatrician] said that we end up feeling all good about ourselves, but then there are all these other bureaucratic aspects. They were talking about how they can think that they are doing very good work with the patients but then they send the patients to other areas and the patients have really difficult times. Heather spoke a lot about that what they do really does not matter when the patients are then having to deal with the wider bureaucratic systems (Field Notes, 17 December, 2008, pp. 4-5).

Several weeks later, Verity was brought up in clinic again. Sophia told Anne that she had "gone to the CL Hospital" because she had been refused TB care at the London Hospital (Field Notes, 7 January, 2009, pp. 10-11). Later while we were alone, Sophia bemoaned the fact that there had been no consensus of care for Verity (Field Notes, 7 January, 2009, p. 11). After Verity's transfer back to the CL Hospital, the practitioners at the London Hospital were no longer involved in her care; therefore I never heard anything more about her progress.

The ultimate consequence of Verity's immigration status was that she is partially excluded from care. Thus, while she was in a geographical location wherein HIV and death have been de-coupled, she was not able to take full advantage of the care and biomedical technologies available in that location. For her, death and HIV were still associated. Further to this is the fact that upon its birth, Verity's baby would be entitled to this care as well as UK citizenship; it would not, however, have the same chances of being HIV negative as other babies born to HIV-positive women with unquestionable access to *free* health care in the UK. Following this, and assuming Verity's baby was born and survived, it would have been (if it was discovered to be HIV-positive) irrevocably disadvantaged because of the effects its mother's immigration status had on it prior to its birth.

The actors that prevented and complicated Verity's access to care did not take her health or her unborn baby's future health into consideration when they refused care. Rather, the refusal was directed towards her present-time body; the health of her future self and her potential future baby were not considered as they did not exist within this logic. Verity's case makes clear that the network of care that would enable the prevention of vertical transmission may be interrupted by other networks; for example, that of the legal system (or rather certain practitioners' interpretations of their legal obligations) which does not acknowledge or consider the significance of unborn babies' future potential. So the needs, intentions and goals of one network may make it impossible for the network that would care for the clinic's patients to work.

### **Trauma**

In what follows I will argue that the practitioners worry their patient may disengage with care as a result of a past trauma. I will illustrate how practitioners may come to suspect a patient of being traumatised when the patient's behaviour, in combination with what the practitioners know about

her, suggest that possibility. As will become clear, a patient may become labelled as being (potentially) traumatised if and when the practitioners cannot confirm that she is *not*. In other words, trauma may emerge as a threat to the network of care when its presence cannot be absolutely refuted. The danger that trauma poses to the network of care is that it makes it impossible for the practitioners to predict their patient's behaviour. Thus, the practitioners fear the (future) effects of information that is not accessible to them because the traumatised patient cannot make that information available to them. In this way, the traumatised patient is, according to the practitioners, (potentially) immune to the effects of the caring care that the practitioners would provide her with. The practitioners thus see trauma as a barrier to the provision of care. In what follows I will describe Theodora's time in the clinic which is based on my field notes and an interview. Theodora consented to let me observe all of her consultations with Sophia and I interviewed her once.

Theodora was in her late teens and had come to the UK in 2002 from Angola; she was ten weeks pregnant and had just been informed that she was HIV-positive. According to Theodora's GP, the relationship with the father of her baby had broken down and there were significant social issues.<sup>109</sup> The father was Theodora's first sexual partner and she made it clear that she did not want to have the baby if he had infected her with HIV. Theodora did not have any direct contact with her partner who was either in prison or in a removal centre (the practitioners were not able to establish which one it was during my time in the clinic). Theodora had had a referral for a termination but had not gone through with the procedure. The information they had thus far on the patient concerned Ellen who explained that Theodora had been very reluctant to answer any questions about her family during her appointment booking.<sup>110</sup> Ellen asked Theodora if something had happened to her in Angola, and after being asked, Ellen said that she closed down completely.

As the weeks went on, the healthcare practitioners' concern over Theodora grew. They found it very difficult to get information about her background and

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<sup>109</sup> Theodora had given the MDT permission to contact her GP.

<sup>110</sup> Ellen would usually have an initial appointment with new patients. She would attempt to gather as much information as possible on the patient during this meeting. These appointments would take place outside the normal HIV specialist clinic sessions.

her relationships outside the clinic. Their concern, I argue, was based on Theodora's behaviour towards them — her reluctance to speak and otherwise engage with care (she refused to take a psychological assessment and would regularly refuse or delay various procedures), her age, their knowledge of her life and relationships with people in the UK, and the knowledge they had about the political situation in Angola in 2002. All of the information they had on Theodora in combination with her behaviour in the clinic led them to believe that she might be deeply traumatised by her experiences in Angola. The practitioners feared that Theodora might stop engaging in the care they were providing for her.

Theodora agreed to be interviewed by me and to let me sit in on all of her consultations with Sophia; this surprised and pleased Sophia who hoped that her willingness to be interviewed might be a sign that she was starting to feel more comfortable opening up. However, her “cagey” behaviour persisted (Field Notes 18 February, 2009, p. 2).

During her interview with me, Theodora explained that prior to her arrival in the UK she had lived in Angola with several other children and women whose husbands and fathers had been imprisoned. Theodora was unsure if the people she lived with were related to her and, if so, in what way. She now believed that the woman she thought was her mother was in fact her sister. However, she explained that she was not sure because, as she told me, “people lie for no particular reason” (Interview with Theodora, 14 February, 2009, p. 11). When asked if she was still in contact with the woman she had thought was her mother, Theodora said the following:

Ulla: Where does your sister live?

Theodora: What sister?

Ulla: You said the sister you thought was your mother before.

Theodora: Oh, since the *thing*, I don't know.

Ulla: You don't know?

Theodora: I don't know if she is *alive*, I have *no idea*  
(Interview with Theodora, 14 February 2009, p. 30).

Later in the interview I asked the following:

Ulla: During the war did anything bad happen to you, or?

[Theodora shakes her head no]

Ulla: No?

Theodora: Thank God, no. Just to my family. I don't know what happened to them.

Ulla: That's hard; I can tell [she was shaking, trying not to cry]. Have you ever talked to anyone about that? Had anyone to talk to?

Theodora: Just the Home Office when I came, they need to know, they said that they had to know, they ask a lot of questions. That's it.

Ulla: Would you like to speak to somebody about that? Maybe a therapist, or no? [She shakes her head no]. Maybe it could help to talk to somebody? No?

Theodora: *What are they going to do? Bring them back? They can't!*

Ulla: No, but it might help you. No?

Theodora: No, no, I'm good. I need to forget, not talk about it.

(Interview with Theodora, 14 February, 2009, p. 12).

Before I return to the issue of trauma, I would like to clarify here that the patients I interviewed had been informed (in the NHS REC participant information sheet) that they would be able to talk to a trained member of staff if they became upset during the interview.<sup>111</sup> The interview extract above demonstrates how Theodora became upset and that I asked if she wanted to speak to a professional. I fulfilled my responsibilities towards Theodora in regards to the way I formulated the questions in the information sheet. However, I did not (and still do not) feel that my response to Theodora was enough.

My discomfort related to a couple of different issues. Firstly, my uneasiness had to do with the fact that I felt I was asking too much of Theodora and that I

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<sup>111</sup> I have chosen not to attach my "Participant Information Sheet" to this thesis as it reveals the name of the Hospital.

offered nothing worthwhile in exchange for her confidence. Secondly, I felt I was placed in a position where I had to determine if what she told me was likely to cause her to disengage with care at some point. How could I possibly predict her behaviour? Here it is important to state my “contingency plan”, mentioned in Chapter Three. After my interview with each patient I would make an assessment as to whether or not they had told me anything that I thought might warrant a break in confidence. In regards to Theodora, I eventually decided not to tell the practitioners what she had told me. This was because I determined that what she revealed to me was not significantly different from what the practitioners had already deduced about her past. I mention this not because I feel that I made the right decision, rather, I would like to draw attention to the fact that I (perhaps inadvertently) behaved in a way that was similar to the practitioners, in that I tried to anticipate the patient’s future behaviour based on her present-time self. This is interesting considering that it was never my intention to over-identify with the practitioners. Finally, my discomfort has to do with using Theodora’s, or for that matter, any of the patient’s I interviewed, narratives in this thesis. I am not suggesting that women in similar positions should not be research participants, but rather that the inclusion of their narratives (or narratives about them into a research project) is not as straightforward as I believed it could be when I began this project.

Returning to a description of Theodora’s time in the clinic reveals how I emulated the practitioners in regards to Theodora’s behaviour and testimony. The practitioners were constantly trying to assess if Theodora’s taciturn behaviour might foreshadow her complete withdrawal from the clinic.

When [Theodora] had her appointment, a lot of the conversation was about the fact that she is not eating and Sophia was trying to figure out if she was not eating because she didn’t have enough money to buy food, or if she was not eating because she just couldn’t eat, and she was feeling sick, and the patient was really difficult to get information from [...] Sophia is really concerned about [Theodora’s] mental health now; when she came back from the scan, [Theodora] said that they had told

her she is not growing enough, that the baby is on the small side, and Sophia was like, you know, this is what I mean, you have to eat, and during her appointment earlier Sophia asked her when the last time was that she had had a full meal and [Theodora] had said that it had been the previous week; she is not eating much at all, and she is very, very skinny (Field Notes, 18 February, 2009, pp. 10-11).

To reiterate, Theodora's behaviour in the clinic, in combination with what the practitioners knew about her background, led them to fear that the care they wanted to provide her with might be permanently disrupted because of her reactions to some sort of past trauma. Theodora's reluctance to speak made it impossible for the practitioners to assess the validity of their fear. Thus, I argue that according to the practitioners the care that they provide always has the potential to be disrupted by the effects of a patient's past atrocity. It is important to stress here that it was not only Theodora's way of presenting herself in the clinic that concerned the practitioners. Rather, it was her presentation of self in combination with what the practitioners *thought* she might have experienced that led them to have concerns about her.

In the absence of a more extensive personal history, the practitioners create a hypothetical past for the patient based on their knowledge and assumptions about the patient's background (social, culture, religion, as well as political and historical context). In this way, the practitioners' knowledge of the political situation in Angola in 2002 participates in the emergence of Theodora as a potentially traumatised patient. In other words, the traumatised patient emerges in the clinic because of a kind of silence on the part of the patient. The patient is understood by the practitioners to possess vital information; both information that pertains to her virus (as discussed in Chapter Four) and information that concerns her life and relationships outside of the clinic. The practitioners understand a potentially traumatised patient as being incapable of speaking openly, so she becomes unpredictable from the practitioners' perspective. The trauma therefore threatens to disrupt the provision of care.

The practitioners' apprehension should be considered in relation to the discussion in Chapter Four that pertained to the viral load assays and the way

in which the practitioners are obliged to use information they suspect may be inaccurate. It became clear in that argument that the practitioners use technologies that they know might compromise the care they would like to provide. Accordingly, the assessment technologies, patients and other medical professionals are known to be capable of supplying the clinic's practitioners with inaccurate and potentially damaging information on which the practitioners are obliged to base their practice. Here I make a similar argument with Theodora's case: namely that the patient's presentation of self in the clinic, most importantly her testimony, is used as a kind of *technology* that will ideally help the practitioners prevent vertical transmission. Therefore, from the practitioner's perspective, a patient who does not provide a testimony and thus speak her trauma (if she is suspected of being traumatised) is potentially risky, in a way similar to a *misreading* viral load assay.

However, I argue that there is a complication inherent to the practitioners' approach, specifically in that those patients who are suspected of being traumatised will never fully be able to refute this suspicion. This is because a traumatised patient may be incapable of *speaking her trauma*. So, even when the patient *speaks*, her trauma is suspected of not having been *fully* spoken. Similar to the practitioners, when I mulled over everything Theodora had said during our interview, I determined that her assertion that nothing bad happened to her in Angola did not actually mean that *nothing bad happened to her in Angola*. Instead, I assumed that she could or would not tell me more. Thus, Theodora spoke and refuted a trauma, but in a sense I did not hear her.

As discussed in Chapter Four, the practitioners' knowledge that viral load assays have produced information that was later deemed inaccurate makes them feel apprehensive. In a similar way, patients who have been identified as being (potentially) traumatised will always make the practitioners uneasy. In other words, the patient will never be able to either refute the practitioners' suspicions, or in any way assure the practitioners that they will be able to predict the implications of her trauma on her care in the present. Only when the failure or success of the practitioners' efforts to prevent vertical transmission is established can the practitioners assess whether or not the

patient's trauma had a negative impact on the care they provided. However, this assessment of the provision of past care is complicated because as mentioned previously, the effects of care are always subject to reinterpretation. In this way, we can begin to see the significance of the temporality of the care provided to patients within the HIV diaspora. I will explore the notion of temporality in more detail later.

As mentioned before, from the practitioners' perspective, they must have a level of trust in the patient's presentation of self in order to provide care. In other words, the practitioners use the patient's narrative to anticipate obstructions to the provision of care in the clinic. For example, if a patient revealed that she believed it was possible to prevent vertical transmission of HIV through prayer, the practitioners would then anticipate a particular kind of threat to care.<sup>112</sup> Or, if the patient revealed that she was without recourse to public funds or any other means of support, the practitioners would be able to anticipate the consequences of this and enable them to initiate defences against these threats. But a patient who is suspected of not sharing potentially vital information, for whatever reason, makes it impossible for the practitioners to appropriately anticipate and contend with threats to their ability to provide care. This concerns the way the provision of care in the clinic requires that practitioners know the patient's story and thus have access to the patient's *truth* in so far as it may affect her time in the clinic. Thus, patients who are suspected of being traumatised and are consequently incapable of speaking *their truths* potentially threaten the network of care.

To conclude this section, I will restate the discussion of Nancy Scheper-Hughes' (1993) work considered in Chapter Four. In that chapter I argued that certain knowledges of the patient's body and life (that the practitioners deem to be relevant to her care) might remain hidden unless the practitioners actively seek them out. This argument was made in relation to viral load machines and how they were "not neutral", nor did they produce "pure sources of data" (Scheper-Hughes, 1993, p. 292). Here I contend that the

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<sup>112</sup> Indeed Fakoya et al. found that nearly one out of the three black African Christians that they surveyed from various denominations in the UK, believed that faith alone had the potential to "cure" HIV (Fakoya et al., 2012).

stories the clinic's patients tell about their lives like the viral load assays and the "public records" discussed by Scheper-Hughes, "reveal a society's particular system of classification. They are not so much mirrors of reality as they are filters" (1993, p. 292). The practitioners would view a patient's presentation of self and the stories she would tell of her life during a consultation not as "mirrors" of the patient's reality. Rather the practitioners would agree with Scheper-Hughes and contend that the patient's presentation of self during consultations is a filtered version of her reality. This version may not contain information that the practitioners would deem vital to care. However, and importantly, the practitioners imagine that they are able to actively *seek out* information that has thus been filtered away. Their ability to do this however, is severely complicated if a patient is traumatised (van der Zaag and McKnight, 2017: forthcoming).

### **Bad care**

This section will be used to show what happens when the network of care is cut or when it was never established. This section will further clarify how care not only concerns just the present time patient, but also it has the potential to enhance or harm her future self, as well as future babies and partners. Cutting the network of care thus puts at risk the practitioners' ability to care for all future patients as well. Moreover, I will illustrate how the MDT's inability to fully protect, anticipate and compensate for the experiences their patients may have (and/or may have had) with professionals external to the clinic, may impede the MDT's ability to provide good care.

Ellen, the HIV specialist midwife, would often refer to a former patient<sup>113</sup> who miscarried under particularly gruesome circumstances. I was given the impression that this patient's experience in many ways exemplified Ellen's concerns about some of the worst things that could happen as a result of the patient's damaging interactions with professionals outside of the clinic. Ellen expanded on these anxieties during our first interview where she spoke about

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<sup>113</sup> To the best of my knowledge I never met this patient. The narration that concerns her is based on conversations and interviews I had with Ellen.

the patient in response to a question that asked if she ever felt anger towards other health care providers.

I felt angry about a woman: she was on the [gynaecology] ward who had lost her baby, [had a] miscarriage. But the baby — the baby [was] delivered in parts and it [was] delivered over about a twenty-four hour period and she was in a side room and it was the night shift, and I think half the baby came out first; I mean it was a *horrific delivery*. And [staff on the ward<sup>114</sup>] wouldn't go near her; there could be stigma about death, because it happens that people avoid women who have got dead babies. That can happen on the labour ward as well, that people don't want to deal with those women. That can happen sometimes — a fear of death and the horribleness of that, and HIV as well. But you know she basically was left to go through that alone and then I picked her up again in the morning and that *really, really angered me, makes me really, really angry* (First Interview with Ellen, the HIV specialist midwife, 21 August, 2008, p. 25).

Later in the interview Ellen once again returned to this patient:

Ulla: Does it ever hurt your feelings personally, if a patient rejects you?

Ellen: I did find it — I had never had a patient reject me so fully as she did or when she actually lost her first baby and I popped in to say that I'm sorry to hear that this happened and I said that sometimes we don't know why this would happen or what the cause is, and she said: "*you are the cause*"! It is quite difficult to be fully rejected; it is quite difficult because it's nice to feel like you can help people, and actually, you do try and help them through and yet sometimes, I'm on a collision course with my information (First Interview with Ellen, the HIV specialist midwife, 21 August, 2008 p. 33).

Here the problem with the patient's rejection of Ellen extends beyond her desire to be liked: it is about how the patient's negative experiences with professionals outside of the clinic may adversely impact on their opinion of the

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<sup>114</sup> The staff in question were not members of the MDT.

clinic, the practitioners within it, and the care provided there. As a direct result of the poor care the patient experienced outside of the clinic, the practitioners' ability to provide the patient with future care is jeopardised. While the patient's miscarriage indicated the end of her pregnancy, it did not, from the practitioners' perspective, end their intention to care for or about her. Rather, the provision of care would have continued assuming the patient would agree to be cared for. Here it is important to clarify that the future baby that I am referring to above is not limited to the unborn baby that died. Rather the future baby pertains to the potential of any and all future pregnancies and babies the patient may have. In addition, there are offspring that a patient may already have. This becomes clear in the following quotation from Ellen:

What I do worry about is where there are women who have got children who are actually being cared for in Africa and we can't do anything about that. We can suggest that they should get tested, but how do they do that? They've got to make a phone call to somebody who they would have to trust or tell [...] the very, sort of sad situation would be that a child gets sick and dies as a result of the fact that we haven't pushed for testing or thought to test (Second interview with Ellen, the HIV specialist midwife 18 March 2009, p. 9).

The process of facilitating the emergence of the imagined relationship with a patient into the future is always a precarious undertaking from the practitioners' perspective. However, the threats could have been minimised in the situation described above had the patient been provided with better, more *caring care* during her miscarriage — in other words, had she not been left so entirely alone to give birth to a disintegrated baby.

Hence, while the practitioners in the clinic are part of a small specialist group that are able to provide well-honed, proficient and sympathetic care, their practice becomes implicated in the way the NHS (or any other (medical) care provider) as a whole provides or fails to provide good care. While the individual members of the MDT may share similar epistemological,

methodological and empathetic approaches to HIV and antenatal care, their patients may not judge the care they receive from the NHS according to each individual clinic in which they are cared for. Therefore, while the MDT devotes a significant amount of time trying to perfect their approach to patients (both medically and empathetically), they are nevertheless at risk of being indistinguishable from more hostile professionals in other parts of the NHS.

The concerns I have described above are highly significant in the specialist clinic because of the practitioners' preoccupation with the patient and her (unborn) baby's potential. Unfavourable feelings about the care she is provided with is known to have the potential to negatively impact on her ability to accept care in the future. Indeed Tariq et al. make a similar observation that HIV-positive Black African women living in the UK with negative experiences with maternity services have the potential to influence their engagement with long-term care and their future decisions in regards to reproduction (2014, p. 59).

Thus, also at stake are all of the patient's future babies and any sexual partners she may have. How the patient comes to terms with HIV and her HIV-positivity is known to have an effect on the way in which she will live her life as an HIV-positive person. Thus, according to the practitioners, whether or not she seeks out specialist (antenatal) HIV care in the future, discloses her HIV status to (potential) sexual partners, makes sure her children are tested, is connected to her experience with HIV (antenatal) care in the present. In other words, a bad experience of care in the present may lead to a woman becoming less likely to engage with care in the future. So, here I am arguing that pregnant HIV-positive women are cared for by the practitioners as if they exist within networks of people who are or may be (the practitioners imagine): alive, unborn, HIV- positive, HIV-negative, with a chance of being born free of HIV or not, in countries with access to ARVs and appropriate care or not, potential future patients in the clinic or the wider NHS or not. Importantly, the practitioners think about the effects their care may have on all of these hypothetical "people", seeking to avoid bad care and to continually assess themselves in relation to their image of good care. In other words, the

practitioners imagine that the care they provide may directly impact on the health of an immeasurable number of people.

This point enables me to extend the argument I made in the previous chapter in regards to patient autonomy. Concern for these future patients provides an example of how a logic of choice, as Mol (2008) has described it, is not conducive to the specificities of HIV antenatal care. As Mol argues, after the initial appeal of being offered a choice has worn off and reality sets in, it becomes clear that choice, in relation to specialist HIV antenatal care, does not offer the pregnant HIV-positive woman autonomy because she is not (nor will she be cared for as if she is) an autonomous individual (2008, p. 74). Rather, HIV-positive women with reproductive capabilities will always be potential future patients in the specialist antenatal clinic. Moreover, the wellbeing of their potential future offspring and any future sexual partners will always be relevant. Therefore, attached to the present-time patient is an un-established amount of potential bodies and patients. The practitioners advocate for these eventual bodies and consequently, the present-time patient cannot be autonomous because she is not cared for as if her HIV was confined in her body. Instead, the present-time patient functions as a sort of *ground zero* in the clinic. By this I mean that an implication of her HIV-positivity is that she is inevitably connected to other HIV-positive people who may or may not know their status. Moreover, her HIV-positivity and her reproductive capabilities means that other (HIV-positive or negative) bodies have the potential to *emerge* from her. Consequently, the practitioners are never finally able to assess the relative success or failure of the care they provide patients with.<sup>115</sup>

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<sup>115</sup> Instead the practitioners would view certain moments of care as either having failed or been successful. Thus, they would say that Patient X's last course through the clinic was successful and this may remain *true* until something untoward happens in relation to her care, or her engagement with care in the future.

## Conclusion

Pregnant HIV-positive patients are often asked and required to accept interventions in order to enhance their unborn babies' chances of becoming HIV-negative and not specifically or necessarily for their own bodies' benefit — for example, in the case of HIV-positive women who never needed to take ARVs prior to becoming pregnant. As discussed in Chapter Two, once a woman has *chosen* to become a patient of the clinic from the perspective of the practitioners, any further choices she makes during her pregnancy will be divided into two possible categories: 1) those choices that align with the practitioners' understanding of behaviour that has the potential to facilitate the best possible outcomes for the imagined future postnatal patient and her baby, or 2) those that do not. In relation to this, Ellen expressed during an interview how she does not want the present time patient to get in the way of what she knows the imagined future patient and her (hopefully HIV-negative) baby have the potential to become.

Because we have a baby on board too, and I would feel awful it's quite hard when there is a positive baby, because you have such a sense of failure about that, because what we've got does work, and I'd hate — somebody because of their belief system or because of their emotion at the time — that they couldn't do the right thing so that they ended up with a positive baby because you don't want them to be in that position (First Interview with Ellen, the HIV specialist midwife, 21 August 2008, p. 33).

In order to achieve this end, it is apparent that the logic of care in the clinic requires that the practitioners engage in practical activities that they believe will make the lives of their patients better (Mol, 2008, p. 75). In this chapter, I have been emphasising that this logic of care is also a *network* of care and what has been demonstrated is that the practitioners imagine that there are numerous threats to this network. The way in which the practitioners anticipate and contend with these threats emphasises how they place a tremendous amount of importance on the relationships they are able to establish and maintain with patients. At best these relationships would enable

the practitioners to provide care despite constant threats to the network of care. Moreover, echoing and extending Mol's contention that within the logic of care, the exactitudes of what a better life would entail "form part of [practice]" (2008, p. 75), I have highlighted that some of the relevant actors are not yet in existence, which leads to the practitioners advocating on behalf of only imagined potential actors. The practitioners' desired outcome of this significant proposition is reflected in the extract below:

What is nice about this job is that you get the relationship, [the women] pop by to see me with their babies or I see them at DOSH when they are about four years old or whatever. It's rewarding if you can help somebody's situation get better; there is a real joy in that so it's not all doom and gloom. *Some of them come along and they're in their next pregnancy and I've known them from before and it can be quite fun* (First Interview with Ellen, the HIV specialist midwife, 21 August, 2008, pp. 34-35).

Ellen's articulations are important and illustrate how, from her perspective, it is the work that the practitioners do during a patient's initial experience in the clinic that enable their subsequent pregnancies to be "enjoyable". This mode of operation in the clinic is informed by the practitioners' collective experiences with providing successful care to their patients. In other words, the practitioners know that they have the ability to provide good care and they know that the (future) patient and her (future) children will reap the benefits if she can be persuaded to acquiesce to it, and importantly, if no other actors (or other networks) interfere with the provision of care.

This chapter has provided a series of key examples of events and situations that disrupted the provision of care in the clinic and has shown how the practitioners constantly try to anticipate and counteract these threats. First, the chapter showed that the network of care has to be established in relation to existent networks. The women patients are themselves in networks that extend beyond the clinic. Not least, most exist within a diasporic network. On the one hand, this threatens their care in the sense that the looming threat of deportation may affect their choices in the present. The chapter argued that

the clinic must care for the “near future” patient, and it negotiates — sometimes even creates — emotional scenarios in order to achieve that goal, even as the practitioners know they have no significant influence over the legal situation. On the other hand, living within an HIV diaspora may threaten the care the clinic aspires to if the patient has family members — including other children — still living overseas. Here, the practitioners feel they must “cut the network” themselves in relation to those members.

Secondly, the chapter focused on the case of Verity where the unequal distribution of knowledge and specialisms across the NHS network meant that different understandings of the care available free of charge to a woman with her immigration status threatened to disallow access to the best care for her condition. This, coupled with restrictions arising from her residential location and exacerbated by her difficulties in accessing the correct drugs from the pharmacy, showed how the care provided in the clinic is threatened by other professionals within the NHS. Moreover, the case underscored that the network that the practitioners would wish to set up for such a case — that would include the baby’s care in the future — were not considered by other parts of the NHS.

A third way in which the network of care is threatened was shown through the example of Theodora. Her case illustrated the idea that a patient who may be suffering from a traumatic experience in the past can cause worry on behalf of the practitioners who fear her trauma may prevent their ability to offer care. It was shown how the practitioners fear that a traumatised patient may involuntarily filter information away from the practitioners — information that may be vital to their provision of care.

Fourthly, the network of care can be cut by other professionals lacking the same understanding or standards of care for HIV-positive mothers. This threatens the network of care not only by making the mothers upset or angry, but it also threatens the future network that the practitioners imagine is likewise within their remit of care. This section enabled me to argue that the practitioners also place the women patients within imagined future networks.

Additionally, this chapter has demonstrated that the practitioners' ability and desire to provide good specialist HIV antenatal care is not enough to ensure the provision of care. This is hugely significant and alludes to the fact that being a patient of the clinic is not necessarily enough for the patients. In other words, the successful prevention of vertical transmission of HIV and the provision of good care is not enough to ensure that the clinic's patients or her offspring will be able to decouple HIV from death. To reiterate the importance of this argument: the practitioners imagine the future patient and her offspring as they have the potential to become and they engage in caring practices that will ideally enable these figures to emerge. However, this entire process depends on the woman being able to accept care now and in the future. The ability to accept care in the future is a rare privilege that many of the clinic's present-time patients know they will not have. The next chapter will consider, amongst other things, what it means to live with the knowledge that your life and your children's lives are entirely dependent on your access to care.

Thus, the discussion in this chapter has begun to outline an argument that will be furthered in Chapter Six: namely, that while the ability to prevent vertical transmission of HIV is an outstanding achievement, it is important to keep in mind that the (HIV-negative) babies of HIV-positive mothers are still at risk of morbidity and mortality as a consequence of their mothers' serological status, if the mothers do not have continued access to life-sustaining care and ARVs. Consequently, from the patient's perspective, the provision of good care and the prevention of vertical transmission of HIV is not enough to secure her life or the life of her baby.

## Chapter Six: Uncertain future(s)

“Ulla: Do you think that you’ll tell<sup>116</sup> your [child] when he’s older?”

Elisabeth: No, I think I’ll take it to my grave.

Ulla: Are you worried that he would treat you differently?

Elisabeth: No, I don’t think he would. But it’s just the fear, protecting him. Because I want to protect him. Because they will treat him differently, and I have *seen it!* At times, with some of the cousins, the way they will behave, and it’s because they know that I am, they figure: Oh maybe even the child? So stay clear of him, don’t move his stuff (First interview with Elisabeth, 17 December, 2008 p. 13)!

It is just people from my own country; I think they have probably seen other people around that have [HIV]. So when they ask you they are just trying to snoop. They are just trying to dig deeper; they ask you what kind of birth did you have, was it a C-section or a normal birth? [...] Once they know you had a C-section, and now you are bottle-feeding, they say *now we know* (Second interview with Elisabeth, 6 May, 2009 pp. 1-2)!

This chapter will consider the key fears and concerns expressed during interviews with the women attending the clinic. These fears and concerns reveal the complexities of the women’s negotiations of the care on offer in the UK. While the practitioners imagine the postnatal woman and her hopefully HIV-negative future baby in a certain way, and imagine their task in terms of facilitating that outcome through the biomedicines and technologies they are able to provide, the women are negotiating these within the context of other relations as they confront their future. These relations are not confined to the clinic but involve their partners, families and legal authorities. The way in

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<sup>116</sup> That she is HIV-positive.

which the women imagine their futures (and the futures of their offspring) involve all these relations which are frequently tense especially where the women have precarious immigration status and where they believe levels of HIV acceptance in their “home” countries is low. Consequently, the women are not really able to make their decisions autonomously. The choices they make in relation to their own health have to be seen through the prism of these complex relations.

This chapter will help clarify what is at stake for these women whose lives, children’s lives and general wellbeing are so entirely dependent on the care, biomedicines and technologies they are receiving. It becomes especially clear that being part of the HIV diaspora affects all aspects of their lives. Indeed, I will make an argument for the importance of considering the HIV diaspora as one of the most salient factors in assessing the circumstances of the patients in the clinic. This chapter will discuss these prominent fears or concerns in four sections: first, in regards to the shadow that fears about being deported casts over the women’s lives; secondly, the way in which replacement feeding — a cornerstone of HIV prevention — becomes problematic; thirdly, the challenges for those women who live with serodiscordant relationships, and finally the role that violence has played in the lives of the women.

### **Imagining a future or imagining death: Fears about immigration status**

In this section I will address some of the questions posed in Chapter Two: namely, how can we make sense of the significance of place and space and the effects of the movement of people between spaces, and the significance of the previous spaces that they occupied? These questions arose after it became clear to me that the majority of the clinic’s patients were highly aware that their HIV-positivity meant their lives would be considerably worse (if not impossible) if they were not able to remain in the UK.

In regards to this, all of the women who had a tenuous immigration<sup>117</sup> status expressed their fear at some point of being “sent home”, which was for them synonymous with being sentenced to death. Accordingly, as mentioned before, women who felt themselves to be at risk of deportation realised that they would not have indefinite access to the kind of (biomedical) technologies and care available to them in the clinic and at the DOSH. Consequently, the way in which the women imagined their potential was intractably related to their ability to remain in a location wherein HIV and death have been decoupled. Moreover, it will become clear throughout this discussion that fear of deportation (in the future) has a significant effect on the way women come to terms with HIV-positivity and adapt to antenatal care and becoming a mother (Anderson and Doyal, 2004, p. 101).

In other words, the women’s ability to imagine a future for themselves or a future-self was dictated by their immigration status. This is because women living with HIV who have an insecure claim to remain in the UK struggle with the knowledge that their lives and the lives of their (unborn) babies have two different possibilities that are entirely tied to location. Following this, while securing a baby’s HIV-negativity was a desirable achievement for the women I interviewed, a baby’s life would still be under threat because of the effects of its mother’s HIV status. If she is deported, the mother’s potential or eventual death would be the most extreme effect of HIV on the baby’s life. Thus, while the prevention of vertical transmission enables babies born to HIV-positive mothers to live free of HIV, it does not in and of itself protect the baby from the effects of the virus — the ultimate one being the death of both mother and child.

Because she is aware of this precarious situation, an HIV-positive mother who is at risk of being removed from the UK simultaneously negotiates her own *and* her children’s future potential in two geographic locations. Following this, I argue that HIV-positive mothers in the clinic are tasked with the responsibility

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<sup>117</sup> The practitioners in the clinic would categorise their patients as either having “secure immigration status” or “insecure status”. Insecure status could denote patients whose immigration status was unknown (by the practitioners) or if they were not in the UK legally and/or had not made themselves known to immigration services.

of participating in the prevention of vertical transmission as well as protecting their descendants from the negative effects of HIV even if prevention is successful. To reiterate and to stress the significance of this undertaking, women thus positioned need to contend with the fact that their offspring would be made more vulnerable if their HIV status was generally known, and if their progeny are suspected of also being infected. What is more, the women would also need to take into account the effects their own deaths would have on their children's lives. What follows is a discussion of the way three women I interviewed (Eleanor, Alegra and Evelina) spoke about the importance of their geographical location.

Eleanor had been raped by her brother-in-law and was frightened of being sent back to her country of origin in East Africa. She explained that she had seen what her life would be like as an HIV-positive person there. After witnessing her sister's rapid physical deterioration and suffering, Eleanor began to suspect that the three of them were HIV-positive. Eleanor knew that a similar demise would befall her if she was forced to return to East Africa.

I can't go back home no matter what, honestly. If it means sleeping on the streets, I'll sleep on the streets 'cause I can't go there; it's like they are sending me to go and die [...] it's a matter of life and death. So I have to choose, if I'm going I have to choose, I'm going to die and I don't want to die now (Second interview with Eleanor, 16 December, 2008, p. 28)!

Eleanor's concern reflects Anderson's and Doyal's discussion of the way in which previous experiences with HIV may influence how people living with HIV come to terms with their diagnosis (2004, p. 96). Similarly, Alegra's fears for the future were compounded by her immigration status. She explained that her ability to live and to imagine a future for herself was dependent on being able to stay in the UK. Her solicitor had made an application on her behalf for permanent residency, citing her medical status as the incentive. However, she had been told that the Home Office had rejected her case. I asked Alegra how this made her feel.

You living here illegally is not good! They can send you back to your country and what should happen to me? *Just die!* [...] If they send me back I'm not going to live, but if I'm here I will live, I can work also, I can do everything people are doing here but not in Africa (Second Interview with Alegra, 21 April, 2009, p. 11).

The conviction that their lives would end horribly and quickly if they were deported made it impossible for the women thus positioned to imagine an optimistic future for themselves or for their children. Being an HIV-positive mother in their countries of origin was for them synonymous with death and the abandonment of their children. In other words, the women are expressing what it means to know that your life is dependent on living in a location you have no legal right to remain in. In relation to this, Cooper and Bradshaw argue that fear of deportation may further damage pregnant asylum seekers in the UK in regards to their mental and physical health (2013, p. 1046). Thus, fear of the future has a real and immediate effect on the women's lives in the present.

Evelina expressed these sentiments during our interview where she explained how her diagnosis had ended her dream of making a better life for herself and her children. She was petrified of being deported. Evelina thought that if she were not HIV-positive, it would be very difficult, but just manageable, to support two children and herself in Jamaica; being HIV-positive made imagining a life there impossible for her. She did not know who would care for her children if she were to become sick or die. Evelina felt that HIV was tolerable now, only because she had the support of the practitioners at the DOSH and access to medication. She doubted that this would be available to her in Jamaica. HIV had taken away Evelina's ability to envisage a favourable life. Moreover, her anxiety extended beyond the prevention of vertical transmission of HIV and was related to her ability to raise and support her children. What I would like to draw out of this argument is that the prevention of vertical transmission does not ensure a life for HIV-positive women or their HIV-negative babies. In other words, the successful prevention of vertical

transmission is not enough to prevent an infant from dying as a consequence of HIV. Evelina's statements during our interview reflect these arguments.

I don't really think about life — things that are in the world, because you're just going to go away and leave them. It's just done me different. HIV just [...] I don't have any hopes or dreams. Sometimes I don't really bother (Interview with Evelina, 8 December, 2008, p. 19).

Moreover, Evelina was fearful of what people would think of her if she was forced to return and the effect that this would have on her and her children's lives. She felt that people would be less inclined to help her if she needed it because they would consider her a person who had had an enviable opportunity but squandered it.

They would think that I made a whore of myself [...] They'd think I whored all over the place. That's what they'd think [...] they have a thing like this if you went away [...] you went somewhere where the money was given away so you should have come back with a lot of it (Interview with Evelina, 8 December, 2008, p. 20)!

Evelina fears being excluded from a collective that would normally protect her and her children. Her rejection would result from the fact that people in her home country would think she had failed to take advantage of the privileges that she was assumed to have had temporary access to. Therefore, from Evelina's perspective, failing to be appropriately enhanced by the resources thought to be available in a privileged geographical location — and even worse, becoming HIV-positive — would make any re-admittance and acceptance into her previous geographical location an impossibility. She is thus in limbo, as are her children. Consequently, she is unable to secure decent lives or futures for herself or her children in either location. Evelina's feelings are reflected in Issiaka and colleagues' (2001) argument which states that many women in African countries are dependent on family support networks to care for them if they should fall ill. Following this, they argue that HIV-positive women may not want to disclose their HIV status to members of

their family because caring for an infected person is considered to be “a negative investment” (2001, p. 126).

As discussed in Chapter One, HIV-positive people in different geographical locations have varying access to ART. Following this, Evelina fears being expelled from a particular location wherein she can imagine a tolerable life as an HIV-positive mother. Another consequence of Evelina knowing that she could, at any time, be denied access to the UK is that she was never fully able to realise and fulfil her potential as an HIV-positive mother in a location wherein HIV is constructed as a manageable lifetime affliction. To clarify, Evelina’s narrative evidences her awareness of the multiple possibilities for what her life as an HIV-positive woman and mother might be. What is more, Evelina’s statements illustrate that she considers her immigration status to be one of the most crucial aspects that determines which of these possibilities will befall her.

To reiterate, a consequence of this is that women thus positioned are never entirely able to take advantage of or be enhanced by resources that may be temporarily on offer to them. This is in part because they are not able to imagine their future selves (or their future offspring) as having sustained and uncontested access to life-sustaining and enhancing resources. Accordingly, an HIV-positive (pregnant) woman’s future self has two possibilities for what she and her children may become (if her immigration status is insecure and if she is at risk of being sent back to a country where ART and appropriate care is not readily available): that of being dead (sent “home”) or alive (in the UK).

Here it is important to stress that being enhanced by biomedical technologies and care ostensibly on offer is not simply about the content or expanse of a patient’s imagination or her behaviour. Rather, I argue that the diasporic positionality of the women I interviewed placed all sorts of other restrictions and burdens on them, the most significant of which was that they were excluded from modes of protection (primarily legal and social protection) available to women who are not part of a diaspora. It is, I argue, the lived experience of what this exclusion entails that impinges on the women’s

expectations for the future. This, I contend, is particularly significant when thought of in relation to the levels of violence most of the women were subjected to on a regular basis.<sup>118</sup>

Moreover, women thus positioned must constantly attempt to negotiate and coordinate between these contrasting locations and their differing expectations in them. As discussed in the previous chapter, Sophia summed up the essence of this when I asked her to expand upon a statement she had made to Yamea. Sophia had explained that the patient's fear of dying would be appropriate if she were in Africa, but as long as she was able to remain in the UK, she could expect to live if she acquiesced to treatment (First interview with Sophia, the HIV specialist doctor, 30 September, 2008, p. 12). The point being that this fact indelibly complicates the women's ability to fully immerse themselves in the technologies and care (temporarily) available to them. Moreover, as discussed in Chapter Four, even if a woman were to fully immerse herself in the technologies on offer, the technologies also have the ability to limit their potential enhancement.

This is important, and I suggest it could have significant effects on the way in which women thus positioned adapt to motherhood as well as come to terms with their HIV diagnosis and use the HIV prevention and detection technologies available. These concerns are reminiscent of an observation made by Valle and Levy. They argue that the meaning that African American women in the USA place on their new diagnosis has an impact on the way they will come to accept or reject HIV care (Valle and Levy, 2008, p. 131). Although, for Evelina and other women similarly positioned, their diagnosis meant that the futures they had previously imagined were no longer possible. From the women's perspective, an HIV diagnosis in combination with the risk

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<sup>118</sup> Indeed all of the women that I interviewed were in, or had been in physically and/or emotionally violent relationships. Moreover, in a study based at an East London HIV clinic Dhairywan et al. (2013) found that one out of eight of the HIV-positive women they surveyed had experienced "intimate partner violence" during pregnancy.

of deportation meant the irrevocable end of their ability to be a good mother and secure an adequate future for their children and themselves.

### **Replacement feeding: Prevention or detection technology?**

Well, to be honest with you, I actually have issues with breastfeeding<sup>119</sup> because it's really difficult when you know that this woman is positive and she's been given that choice, but actually the choice is really more to do with what's best for the child. So if they're coming from an area [in South Africa] where there's no clean water and they can't clean, sterilise the bottles and all that, the chances [are] that the child is going to die of gastro-enteritis or some other problem much quicker than HIV, so in that way it makes sense that they breastfeed. But it is hard, isn't it? Because you know that actually we are trying to reduce the risk and you are *breastfeeding!* (Interview with Laura, an HIV specialist paediatric nurse, 29 January 2009, p. 19)!

Breast milk is a transmission source of HIV.<sup>120</sup> Therefore, HIV-positive mothers are able to avoid exposing their infants to HIV-contaminated breast milk if they replacement feed them, which the World Health Organisation (WHO) defines as “the process of feeding a child who is not receiving any breast milk with a diet that provides all the nutrients the child needs” (2010, p. 45; Dunn et al., 1992). According to the WHO's encompassing definition of replacement feeding, it is essentially any method of feeding using any substance aside from the infant's mother's breast milk. However, replacement feeding is not advised for all HIV-positive mothers. The WHO writes that this method is only advised for women who are able to fulfil the following criteria:

Mothers known to be HIV-infected should only give commercial infant formula milk as a replacement feed to their HIV-uninfected infants or

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<sup>119</sup> In addition to her work in London, Laura works with HIV-positive children in South Africa. During our interview she spoke about HIV care in South Africa and the fact that HIV-positive mothers are advised to breastfeed.

<sup>120</sup> According to the Nduati et al. (2000), if a mother is not on ART then the risk of vertical transmission of HIV through breast milk is about 16%.

infants who are of unknown HIV status, when specific conditions are met:

- a. safe water and sanitation are assured at the household level and in the community; and
- b. the mother, or other caregiver can reliably provide sufficient infant formula milk to support normal growth and development of the infant; and
- c. the mother or caregiver can prepare it cleanly and frequently enough so that it is safe and carries a low risk of diarrhoea and malnutrition; and
- d. the mother or caregiver can, in the first six months, exclusively give infant formula milk; and
- e. the family is supportive of this practice; and
- f. the mother or caregiver can access health care that offers comprehensive child health services (WHO, 2010, p. 37).

National authorities in countries where women are generally not able to fulfil the requirements for safe replacement feeding are advised by the WHO to promote exclusive breastfeeding to HIV-positive women and their infants, for six months after birth (WHO, 2010; Goga et al., 2012). Thereafter women are counselled to introduce other foods while continuing to breastfeed for at least a further six months.<sup>121</sup> In order to reduce the risk of infants becoming infected with HIV, women and/or their infants are advised to take ART throughout the breastfeeding period (WHO, 2010). This will reduce the risk of transmission of HIV to between 0%-6% (Tariq et al., 2016; Horvath et al., 2009; Siegfried et al., 2011).

As this advice shows, replacement feeding is understood as providing HIV-positive mothers with an alternative way to feed their infants non-contaminated breast milk. Accordingly, replacement feeding is able to ensure health, if health is defined as the absence of HIV. However, replacement feeding is not able to guarantee *health* if health is defined as anything else, such as the absence of cholera, or typhoid, etcetera. Rather, in these

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<sup>121</sup> For a discussion on the often conflicting advice on replacement feeding given to women in resource-poor settings please see: de Paoli et al., 2002 and Moland et al., 2010.

circumstances it can be seen to be the *cause* of these morbidities (Coovadia et al., 2007; Iliff et al., 2005). Thus, infants of mothers unable to fulfil the requirements for safe replacement feeding are at a more immediate risk of mortality from other illnesses such as diarrhoea, than they are of dying from an HIV-related illness.

In this way, HIV prevention technologies can be assessed as health promoting technologies by a set of indicators (de Laet and Mol, 2000, pp. 231-233). Replacement feeding's health indicators concern HIV transmission through breast milk, but only for specific groups of HIV-positive mothers. For mothers not part of these groups, it would be more appropriate to speak of replacement feedings' mortality indicators which concern malnutrition, waterborne bacteria and illnesses, etcetera. Hence, the process of comparing alternatives is a specific procedure that may have variable outcomes depending on any number of factors. However, in this example, access to certain resources (which is almost interchangeable with geographical location) is the most prominent influence. Here we see a clear geographical divide that has to do with access to resources between HIV-positive women who are able to secure their infants' negative HIV status and lives by feeding them artificial milk, and women who are not.

Replacement feeding is a technology<sup>122</sup> that can in certain circumstances (which are almost entirely connected to geographical location) protect infants

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<sup>122</sup> A note on replacement feeding as a "technology": in this chapter I refer to replacement feeding as an HIV prevention technology. However, before I continue, I will clarify the way in which I have come to think of it in this way. For ease of expression, I use the phrase "replacement feeding" when it would be more accurate for me to write the "conglomeration of the various instruments that are used to facilitate replacement feeding". These instruments could include spoons, cups, bottles, bottle sterilisers, kettles to boil water and so on. Importantly, however, is the fact that while what these instruments are and how they may be used can vary, the final product would always be the same: the final product being an object that is able to make and convey replacement milk into the mouth of a baby. Thus, "replacement feeding", as I have defined it is a technology in a way similar to the bush pump, described by de Laet and Mol (2000). They write that the boundaries of the Zimbabwean bush pump are multiple and that each of the boundaries of the pump "define a limited set of configurations" (2000, p. 237). "They each, one might say, enact a different bush pump" (2000, pp. 237- 238). Thus, like de Laet and Mol, who refer to the bush pump as a fluid technology, I am thinking of replacement feeding as a "conglomeration of the various instruments that are used to facilitate replacement feeding", i.e. are needed to get replacement milk into a baby.

from morbidity and mortality, while in other circumstances it cannot. Consequently, the meaning and effects of replacement feeding vary depending on the geographical location wherein it is used *and* on the original geographical location of the women who use it, as will become clear later in this chapter. Indeed, replacement feeding like the viral load assays discussed in Chapter Four is not a neutral technology (Scheper-Hughes 1993, p. 292). Instead, and restating the argument made previously, technologies “reveal a society’s particular system of classification” (1993, p. 292) and here I argue that they do even more than that since some of the technologies’ effects reveal global inequalities and their consequences.

I argue that while replacement feeding may at first glance seem like the most straightforward HIV prevention technology on offer to HIV-positive mothers (who are located in geographical locations where it is advised), it is in fact a highly complex and contentious technology that also has the ability to harm women and their offspring. In other words, I will show that replacement feeding as an HIV prevention technology’s potential (to harm or help) is delimited by and connected to the particular circumstances and the (previous) geographical location of the women that engage with it, furthering the argument made previously that HIV and HIV (prevention) technologies have different meanings and effects for people who engage with them depending on their incorporation within the HIV diaspora. This also means that preventing HIV, and the morbidity and mortality associated with it, not only concerns access to biomedical technologies such as ART or appropriate care, but also to other conditions and circumstances that occur almost exclusively in specific geographic locations.

In what follows, I will discuss two women’s problematic experiences with replacement feeding. I will argue that the difficulties they encountered are directly related to the way their families and communities used “replacement feeding” as an *HIV detection device*.<sup>123</sup> Moreover, it will become clear that the technology is used in this way as a direct result of the meaning that it is

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<sup>123</sup> Tariq et al. (2016) have made a similar argument as will be discussed below.

imbued with as a consequence of its position within the diaspora. To reiterate, the technology has a fluid meaning in that it is simultaneously an HIV prevention and a detection technology within specific diasporic communities.<sup>124</sup> In part this is because HIV positivity is not the only, or necessarily the most immediate threat that they must protect their infants or themselves from. Here we see how the prevention of vertical transmission of HIV loses some of its significance when thought of in relation to the complexities inherent to living life as an HIV-positive mother.

### **Eleanor**

I was on the bus, [the new-born] was crying. I tried everything. I gave her a dummy. So this [African] lady, she wanted me to give her milk. I had milk, but it was too hot [...] so this lady says “the baby is crying too much, give her the breast, don’t be afraid of everyone; come sit here, give her the breast.” That’s what she was telling me, you know, “give her the breast, sit there, don’t be ashamed!” I looked at her and said, “no, she doesn’t want breast, I have given her food already”. One thing that lady kept saying to me, one thing I cannot understand, she kept on saying “my baby is crying” — I didn’t like it, I ended up insulting her. I told her I am the mom, I know best. Because she kept on insisting that I give the baby breast and that really just affected me and offended me [...] I had to get off at this stop where I was not getting off because people were looking at me (Third interview with Eleanor, 7 May, p 16)!

Eleanor and I met during the first trimester of her second pregnancy. As I came to know her over the course of her pregnancy (and postnatally) I felt increasingly saddened by the mounting hopelessness she expressed over the way her life was turning out. It seemed to me that despite having the best intentions she encountered insurmountable difficulties any way she turned. Eleanor was young, lonely and beautiful and from what she told me about her life, it seemed to me that she would unquestionably trust men who presented

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<sup>124</sup> By this I mean communities that are connected to geographical locations wherein HIV and death are not decoupled and locations where they are.

themselves to her in an authoritative manner. While some of these qualities might have been desirable for a young woman under different circumstances, I felt that they exposed Eleanor to the caprices of men that ultimately took advantage of her gullibility. Consequently, Eleanor was single, pregnant with her second baby, without recourse to public funds in her own right and had little hope of being able to legally remain in the UK.

During our last postnatal interview, Eleanor told me that her mother, who lives in Africa, warned her never to reveal to anyone that she was not breastfeeding her baby. Eleanor's mother explained that people in [their country of origin] would begin to suspect there was something "wrong with [her]", if they knew the truth (Third interview with Eleanor, 7 May, 2009, pp. 16-17). This conversation led Eleanor to believe that her mother suspected her of being HIV-positive, although she had never directly disclosed her status to her mother. Eleanor thought her mother had begun to suspect the truth after she had found out she was replacement feeding. In a similar way, Tariq et al. contend that within African diaspora communities in the UK, the "bottle-fed infant" may become a "visible surrogate marker for an HIV-positive status" (2016, p. 3).<sup>125</sup> Thus, Tariq argues that African HIV-positive mothers fear that their status will be revealed if it is known that they are not breastfeeding (Tariq, 2013, p. 270). Hence, in accordance with her mother's advice, Eleanor came up with elaborate strategies to trick people into thinking that she was breastfeeding. Eleanor's efforts to conceal HIV reflect Anderson's and Doyal's argument that HIV-positive women's perceived need to keep their HIV-positivity a secret often leads them to place major constraints on their social interactions (2004, p. 101-102).<sup>126</sup>

Here it is important to state that not all women in the UK who abstain from breastfeeding would be suspected of being HIV-positive, considering that according to the most recent Infant Feeding Survey, only one in one hundred

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<sup>125</sup> Eide et al., (2006) make a similar argument in relation to HIV-positive mothers in Sub-Saharan Africa.

<sup>126</sup> As Tariq points (2013, p. 270) other researchers have shown that HIV-positive mothers often isolate themselves in an attempt to involuntarily disclose their HIV status (Blystad et al., 2009, Cames et al., 2010; Desclaux et al., 2009; Nuwagaba-Biribonwoha et al., 2006).

mothers in the UK followed the NHS guidelines of exclusively breastfeeding their babies until six months of age (McAndrew et al., 2012, p. 4). In other words, the overwhelming majority of women in the UK replacement feed their babies. Therefore, my argument proposes that the meaning of replacement feeding in Eleanor's situation is tied to her country of origin and the meaning replacement feeding has there. In other words, her mother's concern was triggered by the fact that for her, breastfeeding was the ideal way to sustain an infant. Thus, I suggest that Eleanor felt that her mother had used the fact that she was not breastfeeding as a sign that she was HIV-positive.

### **Elisabeth**

Elisabeth's family and community voiced similar concerns although they did this in a way that was much more harmful to her. Elisabeth was a very well-liked patient. The practitioners would talk enthusiastically about her on the days that she was expected to come in. A large part of Elisabeth's popularity in the clinic stemmed from the fact that she would always bring her charming and precocious son with her. Elisabeth and I grew close during the course of her pregnancy and I subsequently gained insight into the incredibly hostile home environment she came from. Her dedication to her son and his sweet sympathetic nature became more poignant as she began to tell me about the threat of violence that both of them faced on a daily basis from her partner. In what follows, I have chosen to focus on one aspect of Elisabeth's home environment that specifically concerns replacement feeding. However, it is important to point out that Elisabeth had told me that she and her son had suffered sustained and severe physical and emotional abuse at the hands of her husband and lived in constant fear of provoking him.

Elisabeth's extended family suspected her of being HIV-positive and she feared that they would try to ascertain if she was breastfeeding her baby, as well as find out if she had had a C-section. Elisabeth explained that her family would assume that she was HIV-positive if they found out that she was not breastfeeding and that she had not had a vaginal birth. Her concern is

reflected by Burns and colleagues who argue that in the UK, African migrants' understanding regarding HIV is hugely influenced by their experiences with the virus in their home country (2007, pp. 104, 106). However, in Elisabeth's case, it was her family's understanding of HIV, and not her own, that had the most impact on her life.

In regards to this, Elisabeth told me that her family and her partner's family had swarmed around her every time she had been in hospital. After her older child was born and was a few weeks old, one of her relatives came to her house and accused her of having AIDS. Elisabeth felt that her family were trying to force her to admit that she was HIV-positive. She felt that they were not at all concerned about her or her child's wellbeing; they simply wanted to upset her in order to see how she would react to their accusations. Elisabeth anticipated an intensification of the problems she experienced with her family after the birth of her second child.

Aside from her husband, who was, as far as she knew, HIV-negative, Elisabeth had not disclosed her HIV status to anyone in her family, nor did she intend to. Based on what she had previously heard them say and do, she concluded that in order to protect her children, she must hide her status from them even though they suspected her of being positive. Despite not having concrete evidence of her or her son's status, the persecution that Elisabeth and her son endured from their family was extreme and had a monumental impact on her wellbeing. She felt desperately lonely and fearful.

Thus, Elisabeth's child is penalised as being HIV-positive and marked by the stigma of AIDS that is enacted within the family, even though the child was born free of HIV. Hence, if a woman is confirmed to be or suspected of being HIV-positive, HIV will indelibly be connected to her (within her social relations) and to her offspring, even if her progeny are born free of the virus. In this way, HIV (as it is in the woman's body unobservable in real-time) is not limited to the HIV-positive woman's body, even if it is not physically transferred.

Elisabeth asked her husband not to tell anyone that she was not going to breastfeed. He ignored her request and told his parents. Elisabeth's father-in-law phoned her, yelling at her and questioning why she was not breastfeeding his grandchild. She feared that her husband had either told them about her HIV status or that they had figured it out. In this case, disclosure was not contained within a sexual relationship but spread to the larger family. As a result, the violence not only impacted on Elisabeth, but also her child.

Disclosure is understood as something the HIV-positive person has control over — a truth of HIV that remains contained within the body of the one who discloses. However, this story shows that once HIV is spoken and put into discourse, it can be used by other people as a way of controlling or penalising the HIV-positive person and the people connected to her.<sup>127</sup> Dodds and colleagues have made a similar observation in relation to African people living with HIV in the UK (2004, p. 22). They argue that HIV-positive people who are from the “Pan-African community” feared that if their HIV status became known to any individual from that group, the information might be spread further afield in the UK and “back home” (2004, p. 22). Returning to Elisabeth's story, other acquaintances also harassed Elisabeth about not breastfeeding; she sometimes told them that she breastfed the baby at night. She thought that people from her own country pry in that way because they have seen other people go through similar things. Elisabeth believed that they wanted to verify if she was in fact HIV-positive. Many of the women Tariq interviewed expressed similar concerns (2013, p. 270). Accordingly Tariq argues that HIV-positive mothers fear that their HIV status will be revealed if it becomes known that they are not breastfeeding their infants (2013, p. 270).

Moreover, she was often asked if she had a normal birth or not; Elisabeth tried to deflect those questions by asking why they would want to know. However, this strategy was not usually successful. Admitting to having had a

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<sup>127</sup> For discussion on the tremendous influence stigma has on the lives of people living with HIV, please see Alubo, et al. (2002); Weston (2003); Anderson and Doyal (2004), Kalichman et al. (2004), Ostrom et al (2006), Mbugua (2007); Ridge, et al. (2007); Collins et al. (2008); Doyal (2009). However, my argument is that stigma is used by her acquaintances as a tool to control Elisabeth.

caesarean section and not breastfeeding would have been tantamount to a full disclosure of her HIV-positivity. Here it is important to stress that for Elisabeth, being associated with technologies that have the potential to assist in the prevention of vertical transmission simultaneously risks disclosing her status as HIV-positive. This is hugely significant for women thus positioned and I argue that this dilemma harks back to the argument made previously which concerned the way the prevention of vertical transmission is not enough to secure life for HIV-positive women or their children. Rather, Elisabeth and other women in similar positions may in fact risk their own and their children's futures when attempting to prevent vertical transmission of HIV.

According to Elisabeth, her husband was aware that she could not safely breastfeed their children and he did not directly oppose her replacement feeding their baby. However, he essentially created situations where Elisabeth would be confronted with their families' and acquaintances' hostile opposition to her feeding practices. Despite this, Elisabeth did not think that her associates were trying to persuade her to breastfeed her baby; rather she felt they were trying to force her to admit to being HIV-positive. I suggest that Elisabeth felt this way because the only reason why she was not breastfeeding her baby was because of the risk of HIV transmission. Therefore, Elisabeth associated replacement feeding entirely with HIV-positivity and assumed that her family members would as well.<sup>128</sup>

For both Eleanor and Elisabeth, replacement feeding was a signifier of their HIV positivity. In other words, and to use the language of Mol and de Laet, Eleanor and Elisabeth felt that replacement feeding and caesarean sections could be used by their communities as HIV detection devices (de Laet and Mol, 2000, p. 252). Elisabeth's experiences as I have described them show that a technology's fluidity is not necessarily entirely beneficial for all members of its user community. Indeed, Elisabeth's narrative illustrates the complex ways a technology can simultaneously benefit and harm its users.

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<sup>128</sup> As an interesting aside, Elisabeth's husband was not suspected of being HIV-positive. Their child was stigmatised as being HIV-positive, yet the child was born free of HIV. However, her husband did not experience HIV stigma yet his sexual partner was known to be HIV-positive. So here we see another example of a disconnect between a mode of HIV transmission and its stigmatising effects.

Furthermore, her story shows that as “a device installed by the community” one of the “boundaries” of this aspect of its identity is firmly constructed around and generative of an antagonistic way of viewing HIV and HIV-positive mothers (de Laet and Mol, 2000, p. 252). Consequently, in this circumstance, and to continue to use de Laet’s and Mol’s terminology, replacement feeding as a fluid technology “contains”, as a “variant of its environment” (2000, p. 252), both the ability to protect an infant from being exposed to HIV through its mother’s breast milk, and also the ability to disclose its mother’s HIV status and subject her and the infant to the censure of the mother’s family and community. Furthermore, while replacement feeding contains “variant[s] of its environment[s]” these are diasporic, if and when the women that engage with replacement feeding are also situated within the diaspora (de Laet and Mol, 2000, p. 252).

In order to further explore the implications of the arguments made above, I will now consider the way Laura, an HIV specialist paediatric nurse, explained during our interview the steps she would have to go through in order to procure replacement formula for her patients who were not in the UK legally. Laura told me that she would occasionally have to request financial assistance from Social Services for women who did not have the funds to buy replacement formula for their babies. However, for women who were in the UK illegally, accessing these funds was conditional. Similarly, Tariq and colleagues report that many of the African HIV-positive women living in the UK that they interviewed who were without recourse to public funds sited the burden of paying for replacement milk as being a substantial strain on already limited household finances (2016, p. 3).

You can’t just say, well I’m illegal, I want milk! You know, you’re illegal, but we need to get them to get to a point where maybe they’re trying to be legal, so maybe in the meantime get them to get a solicitor; get them to start processing them and their immigration because the fact that they are processing and they are recognised, then at least, because children in this country have rights, any child born here, so I use that as an argument to say “actually, this child has a right to be HIV-negative,

because you know they need to get that chance” (Interview with Laura, an HIV specialist paediatric nurse, 29 January, 2009, p. 17).

What I would like to draw out from the extract above is the complicated situation such HIV-positive women find themselves in. On the one hand, they need to procure replacement milk in order to ensure that their baby remained free of HIV, while on the other hand, exposing themselves to the Home Office (especially if they felt their chances of being granted leave to remain in the UK were slim) would pose a tremendous risk for them and their babies. Hence, not only do the effects of the technologies have the potential to harm the women while simultaneously preventing vertical transmission, but the process of gaining access to the technology may also cause harm. In other words, by making themselves known to the Home Office, the mothers would be exposing themselves to death if they were at risk of being deported to a country where HIV has not been decoupled from death. On the other hand, if they breastfeed their infant they risk exposing the baby to HIV. How to negotiate this predicament?

Added to this is the fact that the rights the child would have as a result of being born in the UK would protect it from exposure to HIV through breast milk but not from having its life put in danger because of other harmful effects connected to its mother’s HIV-positivity.<sup>129</sup> In other words, the rights that Laura says the child would have as a result of being born “here”, would ostensibly protect the child from certain effects of HIV for a period of time (the first six months of the child’s life during which it will exclusively consume replacement milk), but not after this. Moreover, as Verity’s case made clear in the previous chapter, the rights of the child do not (necessarily) have the ability to protect it prior to its birth. In that chapter, I argued that professionals who prevented and complicated Verity’s access to care did not take the health of her “future baby” into consideration because it did not exist within their logic. Following this, it becomes clear that protecting the (unborn) baby from (certain) effects of HIV is not necessarily a task that all of the people that

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<sup>129</sup> Examples of different ways the effects of HIV may harm children and babies will be provided later in this chapter.

would be able to protect the (unborn) baby engage with.<sup>130</sup> I will expand upon and clarify this argument later in this chapter.

While the practitioners acknowledge the dilemma women thus positioned face, their immediate concern is with the prevention of vertical transmission. So, the practitioners know that they have the ability to facilitate the prevention of vertical transmission whereas their patient's potential deportation is beyond their control. Surely, preventing vertical transmission is worth it even if the mother may be removed from the UK as a result?<sup>131</sup> It is important to mention that I am not suggesting that the practitioners' approach is wrong. Rather, my intention is to highlight that the technologies used to prevent vertical transmission have specific consequences for HIV-positive diasporic women. Moreover, I argue that the consequences are part of the technology, if and when women located within the HIV diaspora use the technology. In this way, my position is similar to the argument Rosengarten makes in relation to the "unwanted effects" of ARVs, mentioned previously (2009, pp. 18-19).

While Rosengarten is specifically concerned with the unwanted effects ARVs have on the body of the person taking them, I extend her argument to encompass the unwanted effects replacement feeding may have on HIV-positive women and their children's lives and futures. Thus, I argue that we should think about these unwanted effects of replacement feeding as being part of what replacement feeding *is* for women located within the HIV diaspora. This would require a move away from the idea that it is the patient's "culture" or family that would lead to the stigmatisation of replacement feeding and instead position the decoupling of HIV in some locations, but not in others, as being the real culprit (or source of the problem).

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<sup>130</sup> I would like to stress that I am not arguing that the health of unborn babies *should* be taken into consideration. Rather, my point is to show that the practitioners in the clinic do take its health into consideration while others do not.

<sup>131</sup> Having said this, I do not wish to imply that women get deported because they were patients in the antenatal clinic. Rather, this sentence reflects a possible outcome of Laura's statement.

## Negotiating the burden of serodiscordance

Couples with one person who is HIV-positive and one who is HIV-negative are sometimes called “serodiscordant” or “mixed serostatus” [...]. “Serostatus” refers to whether someone has HIV infection or not (AIDS InfoNet, 2012).

We’ve seen so many patients go through so many different things, so we can kind of, foresee what potential problems there are and you can kind of put them at ease saying “ok you may not have leave to remain in England but there’s other things that we can do, you know, it may be that you haven’t disclosed to your partner and while we don’t advocate that, we understand it” (First interview with Sophia, HIV specialist doctor 30 September 2008, p. 2).

We can’t force disclosure, but we do have a responsibility to help [the patient] do that to the husband, but then there could be dangers as well and those dangers can be very real for some [...] we’ve got sort of a lot of evidence that domestic violence is an issue, with disclosure, so it’s a difficult path to tread and we also have got to think about the legal sides, because clearly there’ve been some court cases where people have gone to prison for not disclosing their status and having unprotected sex with their partner and we have to let people know that that is the case, and document that we’ve told them that, and then be seen to be working towards it (Second interview with Ellen, the HIV specialist midwife, 18 March, 2009, p. 11).

This thesis has previously considered the multiplicity of HIV in various contexts. Here I will add to this discussion by exploring the multiplicity of serodiscordance within the context of the lives of two of the women I interviewed. I will argue that women located within the HIV diaspora who disclose their HIV status to their sexual partner(s) do more than fulfil a legal and moral obligation.<sup>132</sup> Instead, the practice of disclosure has the potential to

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<sup>132</sup> In the UK, serodiscordance is understood as the responsibility of the person who is infected with HIV in a sexual relationship. This responsibility entails that if the person infected

forever subject HIV-positive women (who are incorporated in the HIV diaspora) and their children, to the consequences of HIV in multiple geographical locations. In other words, fulfilling a UK-specific requirement<sup>133</sup> to disclose means the women will (potentially) be subjected to effects of HIV from places outside of the country. In this way, I argue that the components of HIV that are disclosed is connected to (unknown) components elsewhere, outside of the UK, in places where HIV may be something very different than it is and has the potential to be. This in turn changes the effects of the patient and her partner's serological status. Serodiscordance not only concerns the relationships between patients and their sexual partners. Instead serodiscordance concerns many more people who are, have been, or may be in the spaces wherein serodiscordance emerges.

In the quotes above, serodiscordance emerges in multiple ways: in the clinic as an entity that must be negotiated by practitioner and patient alike; as an entity within relationships (both sexual, violent and supportive) between patient and practitioners and between patients and their sexual partners; as a temporal entity; as a legal entity; and as a diasporic entity. In what follows I will provide a description of my interviews with Alegra to begin to clarify the arguments made above.

All the women that I interviewed who were or had been in serodiscordant relationships expressed to me how their partners made them feel *tainted* because of their status. What is more, their bodies were constructed as being an inherent threat to their partners' bodies.

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with HIV fails to disclose s/he can be accused of grievous bodily harm in the UK (Dodds et al., 2005; Weait, 2007). The criminalisation of HIV transmission and its legal force is present in the clinic — made visible by the ethical-legal necessity for practitioners to encourage disclosure even though they know the effects of this may be violent to the women involved (Gielen et al., 1997, 2000; Kalichman et al., 2003).

<sup>133</sup> I am not suggesting that the act of disclosure is specific to the UK. Rather, what I mean is that disclosure in the London Hospital is part of a UK-specific requirement.

## Alegra

I will begin with Alegra, the first woman that I interviewed for this project. The practitioners considered her to be a compliant patient because she appeared to concede to everything they suggested without question. However, Ellen the HIV specialist midwife did express some concern over her apparent docility. Ellen worried that Alegra's compliance veiled issues that might obstruct her care or wellbeing in the future. These sentiments were apparently intensified when Ellen came into the room during our first interview and found Alegra sitting next to me crying inconsolably.<sup>134</sup>

My connection with Alegra grew strong over the course of her pregnancy and antenatal period. The line between researcher and confidant often felt unclear to me as I became more involved in her life. What I found most difficult to contend with was how utterly and completely alone and exposed Alegra felt. Her distress was tangible and overwhelming. She was convinced that she would die a horrible death if and when she was deported and I could not contest the probability of this.

Alegra did not have any experience with HIV prior to finding out that she was HIV-positive several years ago. This occurred when Alegra and her partner

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<sup>134</sup> I reassured Ellen the following week that while Alegra had indeed opened up to me, she had not disclosed anything during our interview that I thought had the potential to adversely affect her engagement with care. It is important to add here that making these judgements about the information patients shared with me was one particularly stressful effect of the interviews I conducted and the relationships I established with the clinic's patients. How could I possibly know what information might foreshadow the patient disengaging in care? How could I be sure that my behaviour during the interview would not have a negative impact on her relationship to the clinic? How could I remain in the role of a researcher (whatever that meant) when confronted with a woman who was so absolutely miserable?

These are questions that I have not resolved in any satisfactory way. Rather, I learned to work with a constant feeling of unease while conducting this project. Further to this, my anxieties illustrate how, like the practitioners, I became concerned over the way my behaviour in the present might affect the women in the future. Moreover, I met with my PhD supervisors after this interview and before the following week's clinic session. We discussed this interview extensively and they were given a transcription of the interview. I was very worried about making judgments regarding if and when I should break research participant confidentiality. My supervisors and I decided that I would refer to them in the first instance, if and when patients said things to me that concerned me. This way, they would help determine and negotiate whether or not I should break the patients' confidence and alert the practitioners to something that the patients had told me. In this way, I came up with a sort of contingency plan.

had been trying to conceive a baby; they experienced difficulties and Alegra had been offered an HIV test. She was subsequently informed that she was positive. Devastated by the results, she told her husband and asked him to test as well. When his results came back negative, she asked him if they could separate. She felt that his reaction to her status was too much for her to bear. Had she been on her own, she thinks she would have been much better able to manage fluctuations in her health. However, he refused to leave, saying that he could not abandon her as she had no one else aside from him and he therefore had to stay with her.

Sometimes I don't even think that I am HIV-positive. I don't mind. I go to school, I do everything all the people are doing. [...] but for him he is really worried, you see. He knows that maybe I can die tomorrow (First interview with Alegra, 22 October, 2008, p. 7).

The extract above explicates how many women diagnosed with illnesses are in a position where contending with their families' opinion about their health is prioritised over their own. This is a consequence of their families' reactions to their diagnosis having a substantial effect on their lives in a more immediate way than the illness itself. Alegra told me that she felt vulnerable being in a serodiscordant relationship. Consequently, she tried to reposition herself in the equation to make it impossible for her husband to claim that she placed him at risk. In regards to this, Alegra said that she no longer had sexual relations with her husband. Moreover, she had gone to great pains to separate all of their belongings. They did not share a bed, nor even linen or utensils. In fact the only thing that they did share was the toilet.

Alegra explained that she was made to feel guilty over being HIV-positive despite the fact that her status was not tied to an act for which she thought she should have to feel culpable. She assured me that she was aware that she would be able to live with HIV (if she could stay in the UK), and that her baby would be able to be HIV-negative. However, she explained that her husband was not able to do the "things" that he would want to do with a partner because of her status. She felt that even if they were to use a

condom, he would eventually blame her (First interview with Alegra, 22 October, 2008, p. 17).

Because he is negative and maybe he have to do a lot of things with a *woman* who wasn't HIV-positive and he can't do that to me [...] Maybe that's why he worried, that's why in the future maybe I can leave him (First interview with Alegra, 22 October, 2008, p. 17).

Alegra stated her belief that her husband needed an HIV-negative wife. She was worried that he would take risks with her that would endanger his health and she therefore felt that it would be better if he could remarry an HIV-negative woman. Accordingly, Alegra attempted to protect her husband from herself, and in so doing protect herself from her husband.

Alegra expanded on this feeling of wanting to separate herself from her family; she said that the experience of being HIV-positive is in itself entirely isolating; even if her family did not want her to distance herself from them, she would. This is why she did not mind that her family lives so far away from her and that she did not have any contact with them. Here again is the idea reported by many women that separating oneself from loved ones is a reasonable way to protect them, and also, in this way, to pre-empt and contend with the (expected) future exclusion and violence. Additionally, being in a serodiscordant relationship enhances any inequalities and discord between the partners.

### **Evelina**

These issues were also evident during my interview with Evelina. Sophia suggested that I interview her because she was very forthright about her circumstances. Evelina had recently given birth to her second baby and her care had, as was the norm, been transferred to the DOSH. She was the only woman that I interviewed and came to know whose pregnancy I did not follow in the specialist antenatal clinic. Despite this, Evelina was, as Sophia had predicted, very open with me about her life.

Evelina was still reeling from the heartbreak she had suffered as a consequence of finding out that she was HIV-positive. She had been infected by her previous partner, whom she had loved dearly and been in a long-term relationship with. She was almost certain that he had known that he was positive and had knowingly put her at risk. Therefore, Evelina ended what she considered to have been a near-perfect relationship and was consequently without a home or a means of support. She was living in the UK illegally and had been able to comfortably support herself and her young son (who was cared for by a relative in Jamaica) with the financial assistance of her ex-partner. She explained that she had felt like a good mother for the duration of her relationship with her ex-partner. The life she had coveted before moving to the UK was within reach and she was in a stable relationship with a wonderful man.

Without explicitly saying so, Evelina implied that her relationship with her current partner and the father of her new baby was dependent on her being sexually available to him. Following this, her living situation felt precarious and unsafe. However, she explained the most devastating repercussion of the end of her previous relationship was that she could no longer send money back home to support her son. Evelina had not felt able to tell him why she had ceased to be in contact and was plagued with worry that he would feel rejected, unloved and would be exposed to neglect.

Evelina told me that her current partner was thought to be HIV-negative.<sup>135</sup> She felt the difficulties inherent in being in a serodiscordant relationship acutely. She believed that although all relationships have their problems, HIV became the focus of all conflicts when a couple was serodiscordant. Evelina said that her partner did not take responsibility for his own safety in protecting himself or getting tested. He left the responsibility of HIV up to Evelina, she said. This was tremendously stressful for her. They recently had a situation where they had sex and the condom they were using broke. Evelina felt

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<sup>135</sup> Evelina did not know for sure if her current partner had ever been tested for HIV.

horrible about it, especially because she had been the one who had initiated having sex. Her partner became incensed with her and accused Evelina of trying to “destroy him” (Interview with Evelina, 8 December, 2008, p. 18). She felt that he blamed her for being HIV-positive. This was particularly distressing for Evelina because of the way she had become positive.

During the interview it became evident that Evelina felt implicated by the derogatory views her partner expressed about HIV-positive people. Additionally, her partner’s inaction to care for himself made Evelina feel as if she was effectively placed in the position of potentially infecting him. From her perspective, she was forced to risk his life when they had sexual relations. Extricating herself from the relationship was not a viable option as Evelina and their baby were entirely dependent on his sporadic support. Moreover, his involvement with her was dependent on Evelina having a sexual relationship with him. For the women thus positioned, being financially dependent on men and having their bodies and HIV-positivity constructed in this way made living as an HIV-positive woman almost insufferable. It is important to stress that another crucial aspect of both Evelina’s and Alegra’s stories are that they were both without recourse to public funds and they felt themselves to be at constant risk of being deported.

Returning to Evelina’s narrative, she did not act in the same way as Alegra in regard to separating herself from friends and family after being diagnosed. In this respect, Evelina told me that talking about being HIV-positive made her feel better about her status. Unfortunately, the people that Evelina had previously disclosed to had reacted badly, and warned her not to tell more people or to talk about it again. This upset Evelina and made her feel even lonelier. Moreover, her partner did not condone the fact that she occasionally went to a group for newly diagnosed people. He implied that only people that were in some way or another “abnormal” went to those groups. Evelina was devastated by his lack of support and wondered if she was in fact the only person like herself who was positive, meaning a heterosexual woman from the Caribbean (First interview with Evelina, 8 December, 2008 p. 25). She feared that her partner might be right and that there was something deviant

and tainted about her. She felt “soiled” and worried that people could sense that she was.

Spending time with other people affected by HIV made her feel better about her lot. However, I suggest that her partner’s criticism of her involvement in HIV support groups alerted Evelina to the fact that there was a significant difference between her and the other participants who were, according to her, either white gay British men or black Africans. I will consider this in more detail after returning to Alegra’s narrative.

Alegra’s desire to separate from her husband intensified after he returned from having his second HIV test. He told Alegra that a clinician at the London Hospital had warned him that he was at risk of becoming infected, simply by living with her. She believes that this was a lie; she assured me that she did not think that he was at risk, but she contended that her status personalised the possibility of her partner becoming infected. Therefore, in lieu of a permanent separation, Alegra decided to secede physically from him. Accordingly, they no longer slept in the same room, or shared utensils or any other household items. She explained that although many doctors contend that HIV cannot be transmitted through casual contact, completely extricating herself from her partner was the only way to absolutely protect him from becoming infected. Following this, Alegra was consequently protected from being accused of potentially infecting him.

This is important, and is a recurring theme for many of the women I interviewed who were or had been in serodiscordant relationships. I suggest that women thus positioned feared infecting their partners, not only out of concern for the partner’s health, but also out of fear of retaliation and exploitation. Here it can be seen that a consequence of having a body that is considered to be risky is that women in these circumstances constantly have to anticipate being subjected to censure and violence. To reiterate, being thus positioned is especially difficult for women who are in some way or another dependent on men for support: all of the women that I interviewed were to varying degrees dependent on men and having sexual relationships with

them, especially those who had an insecure immigration status (and no access to public funds).

Moreover, as discussed in Chapter Four, the way in which Alegra and Evelina negotiated their partners' understanding of HIV and expectations on their behaviour relates to the work that the practitioners do when trying to pre-empt complications caused by patients who resist specialist antenatal care. In that chapter I illustrated how the practitioners reorganised some aspects of their practice in order to accommodate P1's beliefs about HIV. Importantly, however, the practitioners did not compromise the care that they wanted to provide P1 with, as a result of the concessions to their plans for care. Alegra and Evelina do however make tremendous concessions in order to accommodate the serodiscordance that emerged in their relationships.

The work that Alegra engaged in, in order to maintain a physical separation from her husband, does not mean that she believed that her husband was put at risk by sharing her utensils or bed linen. Rather, her concession to his understanding of HIV suggests that she recognised that it could have a negative impact on her if she did not. Further to this, from Allegra's perspective, the *husband* that was at the focus of these negotiations was both her husband as he was now and as he would be if she were to die and he became the sole guardian of their baby. Following this, I argue that Allegra's and Evelina's behaviour in relation to their partners' understanding of HIV was entirely dictated by concerns for their own and their children's wellbeing, now and in the future.<sup>136</sup>

While Alegra was convinced that her husband was not in any immediate risk of becoming infected, he was not persuaded. Consequently, in order to make life tolerable with him she chose to behave as if she did not have the knowledge she did about the virus's modes of transmission. Her much more immediate concern was her husband's perception of her serological status. Her actions reflected his perception of her HIV-positivity (or, rather her

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<sup>136</sup> Please see Wilson (2007) for a discussion of the difficulties involved in being a mother with a chronic illness.

perception of his perception). To reiterate, this is because his behaviour could potentially have a much more immediate effect on her wellbeing. Following this, it can be seen that the version of serodiscordance that emerged within her relationship to her husband was intricately connected to out-dated understandings of HIV and its modes of transmission; the fear of violence; the fear of abandonment and the wellbeing of (unborn) babies. Moreover, all of these components of serodiscordance become more acute because Alegra felt that she was at risk of being deported. This aspect will arise again in the next section which will consider violence.

## **Violence**

In this section I will illustrate how for women located within the HIV diaspora who have leave to remain in the UK and thus have the “freedom” to move from place to place, their diasporic positionality and temporality were not marked by “personal freedom”. Family ties delimited their freedoms forcefully. Indeed, these relationships were frequently laden with oppressive, even violent, gender dynamics to which HIV infection added a further complicated dimension. It will become clear that the patients I interviewed who are located within the HIV diaspora move through different geographical spaces and political economies.

In what follows, I will consider the narratives of two of the women I interviewed: Asa and Kessie. However, it is important to point out that all of the women that I interviewed and the vast majority of women I came in contact with while conducting this project shared horrendous stories of abuse that they had been subjected to.<sup>137</sup> A narration of the women’s experiences as told to me during our interviews, will be followed by a discussion of the ways I have attempted to make sense of their stories. Both Asa and Kessie were originally from countries in Sub-Saharan Africa and had permanent leave to remain in the UK.

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<sup>137</sup> The stories were told to me by the women themselves and/or by the healthcare providers. However, as mentioned above this chapter is based on interviews I conducted with patients.

## Asa

Asa became HIV-positive and pregnant after being raped in London. The rape was arranged by Asa's female cousin as a way of punishing her for a perceived transgression. Asa never criticised the use of rape as a mode of punishment; she did however stress that she was innocent of the transgressions she had been accused of. The accusations concerned Asa's failure to appropriately help her cousin with a manual task. In other words, Asa had been charged with turning her back on a family member in need. Her description of the events left me with the impression that Asa felt that acquaintances of hers had been jealous of her apparent success in the UK. She implied that people assumed she had started to act "above her station" and that she was becoming too independent. Following this, I argue that the attack was used as a way of nullifying her perceived superiority. Further to this, I will suggest that the attack indebted Asa to her family and acquaintances.

Asa believed her cousin knew that the man that carried out the rape was HIV-positive. She explained to me that she now knows that plans for the rape were discussed amongst her acquaintances prior to the attack. Asa is aware of this because her partner knew that the rape was being organised; however, he had not known that Asa was the intended target of it until the day of the incident. He tried to contact Asa and warn her but he was too late. Accordingly, people close to Asa had sanctioned the rape and a woman had arranged it. Asa's experiences demonstrate that organised rape as a form of punishment is a method of social control and as such, both men and women utilise and sanction it.

It is important to stress that one of the things that I found most disturbing about the way Asa spoke to me about the attack was the fact that she appeared to accept that her partner had only tried to prevent it from happening after he found out that she was the intended target. In other words, she felt ingratiated to him because he had not left her, rather than being incensed that he would condone rape. This led me to conclude that she did

not think that his failure to try to prevent the rape of an unidentified woman was indefensible. Following this, it became difficult for me to reconcile my feelings for Asa's partner with the way she spoke of him during the interview and her consultations. He was, according to her, a good, supportive man that she believed would become a decent father. She felt fortunate and grateful that he had chosen to stay with her and agreed to help raise her baby, despite the rape and her HIV-positivity.

Asa went to the sexual health clinic at the London Hospital about a month after the incident, because she was feeling very ill. Shortly thereafter, she started to receive calls from the hospital, asking her to come back for an appointment. Asa was distressed and reluctant to comply with their requests. Her mother, who lived in Nigeria, finally convinced her to return to the clinic. Asa was told that she was HIV-positive. She was devastated and explained that she "was not herself" for some time afterwards. Asa disclosed to her mother who called her regularly and tried to support her, and to a few other family members, including her partner. He had been very sympathetic since the rape. She wanted to separate from him after finding out that she was both HIV-positive and pregnant; she wanted to keep the baby,<sup>138</sup> but was worried about what he might do. Fortunately, she explained, her fears were unfounded and he was pleased that she was pregnant.

Asa had seen the man that raped her several times since it happened. He had also phoned her and tried to apologise. After the incident she contemplated trying to kill him and then committing suicide. She confided in Sophia who convinced her to act differently and to report the rape to the police. Asa told her mother that she planned to report the incident but her mother persuaded her not to. Her mother explained that if Asa was able to live with the consequences of the assault she should leave it in the past. Asa was also concerned that if she were to report it, it would become generally known that she had been raped and that she was HIV-positive. Additionally, her mother

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<sup>138</sup> Although it is important to state that Asa and one other woman I interviewed, Eleanor, did tell me during interviews that they had thought about the possibility of having a termination. Both women became pregnant after being raped by men in their acquaintance. In both cases, the women's mothers convinced them not to take legal action.

pointed out that reporting the rape would make public what they both considered to be a private family issue. As I mentioned previously, this is significant and a recurring theme for the women I interviewed. Asa was asked to abandon her own desire for retribution for the sake of her family's reputation.

Further to this, Asa explained that the consequences of making the rape public would have been dire for her entire family; her HIV-positivity would have become known and her family's internal struggles would have been exposed. All of these revelations would have had negative effects on her whole family including her child and her (unborn) baby. In regards to Asa's mother's request that she keep silent, Yankah argues that the monumental consequences of HIV/AIDS in Africa have made it an "unspeakable" event within "folk discourse" (2004, p. 183). Furthermore, I argue that Asa was placed in a position where she was made to feel gratitude towards (and be indebted to) people for accepting her despite her HIV-positivity and pregnancy. Moreover, anyone who knew about the rape and her HIV-positivity would have a means of extorting and influencing her behaviour in the future. Thus, the rape reaffirmed her family's ability to influence her. Here it is significant to mention that the rape seemed to have brought Asa in closer relationship with her family and her partner. This was indeed the point of the rape: to cut her down to size, to return her to her "right" place within the gendered dynamics of both her partnership and her family. In a sense, the rape "brought her home".

### **Kessie**

There are similarities between Asa and the way Kessie became HIV-positive. Kessie was from a West African country. She moved away from home and became self-sufficient when she was still a child. Although Kessie did not say so directly, the stories she told me about her life left me with the impression that she had supported herself through sex-work. She met a white British man, whom she would later marry, when she was in her late teens. Shortly after the

relationship began he arranged for Kessie to get a visa and she arrived in London soon after. Kessie and her family were delighted; they happily let her move. Kessie explained that her family condoned the relationship because it enabled Kessie to negotiate a “better life” for herself and eventually for them:

We were very poor. [...] when you have many children like that; if a white man [turns up] in Africa, we see them as *God* so if someone like that turn up, it’s a blessing to the family so they can just release you. [...] They were happy; we were all happy (Interview with Kessie, 28 January, 2009, p. 4).

Kessie’s husband started to drink heavily and abuse her shortly after she arrived in London. She was often forced to spend the night in phone booths and police stations, returning home in the early morning after he left for work. Kessie would leave again, before he came home. He was possessive and jealous, fearing that Kessie would leave him for someone closer to her age. Kessie confided in a few of her friends; they told her that this often happens and that it would not be out of the ordinary if he killed her. After being fully informed of the violence she was subjected to, her family advised her to leave him and come back home only if he stopped working. However, fearing for her life, Kessie eventually left her husband and moved back to Ghana where she lived for two years before he started to ask her to come back to London. He assured her that he would change and that her life with him would be better. She returned with him, and the abuse resumed.

Kessie left him again and met the man who would become the father of her children. She became pregnant with her oldest child. Kessie told me she waited several months before she went to an antenatal appointment. She was given an HIV test and a few days later received a letter, asking her to come back to the clinic. She was told that she was HIV-positive. Her response was initially one of disbelief.

Devastated and confused, Kessie called her previous partner, whom she referred to as her “white man” (Interview with Kessie, 28 January, 2009, p. 2).

On telling him that she was HIV-positive, she became suspicious of him when he did not sound surprised or upset. He advised her not to worry too much about it, informing her that now that she was in the UK legally, she would be taken care of and that many people were HIV-positive. Shortly thereafter he phoned Kessie and told her that he had just received a call from the hospital and they told him that he was HIV-positive as well. On hearing this, Kessie became apprehensive. She thought it improbable that he would receive his results over the phone and that this should happen on the same day she had been informed of hers. Kessie explained that she had been naïve; her gullibility prohibited her from trusting her suspicions. Her ex-partner eventually confessed that he had known that he was positive. The extent of his lie was confirmed when she began taking ART and recognised it as the same medication that he had been taking since she first met him. He told her that he had not known how to tell her he was HIV-positive; consequently he had turned to alcohol as a way of appeasing his guilt. He claimed that he had brought her to the UK because he felt guilty about having potentially infected her. After this came to light, Kessie explained that he has always helped her whenever she has been in need. She felt gratitude towards him for his support and she was also thankful that he did in fact enable her relocation to the UK.

*He didn't leave me!* The reason why I'm not so angry with him is that he didn't abandon me in Africa; I would have been dead by now. But he brought me here and he stood beside me and he helped me and I thank God for that. Many, many girls like me have been abandoned like that and they are dead! Many of my friends in Africa that I know of are dead. And then I didn't understand what was killing them, until now. So I tell God if, like he left me there, I would have been dead. But he was so kind with me because of my age, and the way he saw me; he just couldn't leave me there, that's why he brought me here and I think he has given me a second chance of living; [HIV] would have killed me, but he let me live. So I don't get angry with him (Interview Kessie, 28 January, 2009, pp. 8-9).

Kessie is speaking of the complicated situation she is in; she is angry for having been lied to and infected, but she also recognises that things could have been worse for her. Her first husband's continued interest in her is valuable to her and her family, although she cannot feel entirely comfortable with it nor can she disregard it. She was aware of her contradictory feelings towards him:

Sometimes I get angry, but then I have to see it the other way, like he helped me. He gave me a second chance to live in life (Interview Kessie, 28 January, 2009, p. 9).

The decoupling of HIV and death are at stake for Kessie. In her lived reality as an HIV-positive woman Kessie negotiates what she thinks the effects of HIV would be if she were still in her country of origin. What that knowledge does for Kessie who is securely in the UK, is complicate her feelings of anger towards her first husband for knowingly exposing her to HIV. Thus, Kessie acknowledges that he took advantage of her while being simultaneously grateful that he extended his privilege (access to biomedical technologies and care through citizenship) onto her.

I regularly heard stories like the ones above while I was in the clinic. Almost every patient cared for during my time there disclosed some kind of truly harrowing and complex events involving themselves and their close associates. The practitioners in the clinic would often hold the patient's "culture" and/or religion responsible for her behaviour, although it is important to stress that none of the practitioners ever implied that violence was an inherent part of their culture or religion, or that of the women's partners. Rather, the patient's culture or religion would be used as an explanation for the patient's confounding behaviour in response to the events they were subjected to. The women I interviewed seemed to view and respond to violence as if it was a normal part of life, rather than a state of exception. The work of Fassin can us help to think about the women's experiences and choices in a way that does not position culture (whatever its meaning) or religious beliefs as a simplistic explanation of them.

As discussed in Chapter Two, Fassin stresses the importance of attuning to the social and historical contexts in which the “experience of the body” is embedded (2007, p. 226). Accordingly, Asa — and other women with similar histories and experiences — can be considered in a way that pays attention to the circumstances that have led them to be in a situation where these things happen to them as a result of their access to resources. However, here it becomes important once again to mention that while Asa was a member of an immigrant community, she also had permanent residency in the UK. Therefore, she would ostensibly be able to access the same resources as any woman legally residing in the UK would, but yet still she did not fully utilise the services available to her.

Following this, I argue that for women originally from the “non-west” (to use Fassin’s language) who have been able to permanently establish themselves in the west, the fact that they are diasporic will always and indelibly have an effect on the way their lives are enhanced (as discussed earlier in relation to viral load assays) and how they utilise the resources on offer in their new locations. Moreover, the women are also intimately connected to other people whose wellbeing they are often invested in enriching. For example, and in Asa’s case, her oldest child had been left in her home country and was cared for by her extended family. In order to secure her child’s wellbeing, Asa was entirely invested in maintaining a good relationship with her family. In other words, her behaviour was always dictated by the requirements of her child, family and community. Thus Asa, and the other women in similar positions, were tasked with the responsibility of attempting to compensate for the social and historical contexts that dictated the way in which they and their left-behind families experienced their bodies (Fassin, 2007, p. 226).

Thus, while Lindau et al. state that there is a relationship between women’s experience of sexual violence and feeling a lack of control over their sexuality (2006, p. 63), I suggest that Asa’s experiences with sexual violence evidences how *feeling in control* of any aspect of your body or sexuality is not a practice all women take part in. Rather, the interviews I conducted with HIV-positive

women and my time in the clinic left me with the impression that many of the patients I met viewed sex and pregnancy as something that happened to them because they were women. Choice, in regards to having sex, becoming pregnant, considering or having a termination, did not seem to be options for them. Following this, a sense of bodily autonomy as I had previously understood it to relate to the choices a woman (cared for in an NHS clinic) would be offered and be able to make did not seem like meaningful possibilities for most of the patients I met in the clinic.

Thus Asa could not have acted as if she had bodily autonomy (assuming that bodily autonomy would have led her to make the rape public or alternatively, to go against her mother's wishes and terminate the pregnancy) because she simply did not. As I have explained, as a consequence of her diasporic positionality, Asa simultaneously had to negotiate a middle ground between the requirements, possibilities and expectations available to her and her family in their multiple geographic locations. Following this, I argue that for women like Asa and Kessie, (ostensibly) benefiting from various services and institutions on offer in the UK to rape victims and victims of domestic abuse is complicated and diminished because their bodies are the sites onto which (their own, their families and communities') expectations are placed. These expectations are acted out on these women's bodies, and can be violent. But this violence does not necessarily break the relations between the women and their network of relations. In relation to this, Kessie explained that her first husband's financial support maintained her extended family and enabled several of her family members to relocate to the UK. Given her first husband's influence on her family's wellbeing, how could she do anything but continue a relationship with him, on *his* terms? Moreover, within this context it "makes sense" that punishments would be extolled on members who attempt to leave or do not take appropriate care of the communities and families that they are in symbiotic relationships with.

## Conclusion

The women I interviewed had hoped that their relocation to the UK would be beneficial to themselves and their families. Often, women located within the diaspora were the sites onto which they and their families placed dreams of future prosperity. In other words, the move to the UK promised a reward for the self and the family. This reward would be obtainable in the future through sacrifice in the present. For the women I interviewed, the fantasy of this future ended as a result of their HIV diagnosis. Instead the women spoke of themselves as having changed from being full of potential to becoming liabilities for their children and family members (Kelly et al., 2012; Tariq, 2013; Wilson, 2007).

Ultimately the women I interviewed felt that HIV would threaten them and their children, even if vertical transmission of HIV were prevented. Thus, HIV for the women I interviewed not only affects their present but also the way in which they imagine their futures and their children's futures. Moreover, the women understood their geographical location to be the thing that ultimately determines their future possibilities. Thus I have argued that HIV-positivity has the ability to ruin a woman's plans for the future, or even the belief that she has a future.

Further to this, I made clear that for women thus located attempting to prevent vertical transmission of HIV could simultaneously put their lives and their children's lives in danger. In this way, the *unwanted effects* of the technologies that the women engage with become part of what the technology is for women located within the HIV diaspora. I argued that this was true for women within the diaspora because they have to negotiate the meaning of HIV and the technologies used in its management and prevention, in multiple geographic locations.

## Chapter Seven

You've got a woman that has come in, you want [her] to start treatment, she wants to pray, she doesn't believe you she's got [HIV] and the lab tells you her viral load is undetectable. You can spend a long time explaining what undetectable means, and then it's wrong, and it's not only wrong, it's wrong by a couple of thousand times wrong, and you go back to the woman who has been to church, who has done a bit of praying and say: "actually the lab tests are wrong, and you've already got all those things we've talked about [...] You are working with somebody who is in such a different place, that the meaning of the technology to that person is so important to get right" (Interview with Anne, a consultant physician, 11 March 2009, pp. 7-8)!

The overarching purpose of this thesis was to explore the challenges of HIV and successful care in an HIV specialist antenatal clinic in a resource-rich setting. By providing theoretically informed reflections on the contingencies of both offering and receiving care in the clinic, my intention was to make a practical contribution to specialist HIV antenatal care by discovering what successful care required of both patient and practitioner. As mentioned previously, there is a dearth of UK-based qualitative research exploring the vicissitudes of receiving and providing antenatal HIV care. Thus, this thesis offers a unique insight into the experiences of under-researched groups,<sup>139</sup> and in this way makes an important contribution to sociological understandings of antenatal HIV care in the UK. Moreover, this thesis has explicated how the clinic's success in preventing vertical transmission of HIV is entirely dependent on the work that each individual practitioner in the clinic provides, in addition to the biomedical technologies and medicines available in the clinic and the way the clinic's patients adapt to and appropriate the care and technologies on offer.

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<sup>139</sup> Here I am referring to both patient and practitioner.

In this final chapter, I will provide a summary of the research findings previously discussed in this thesis that are of practical use in the clinic and which contribute to sociological knowledge concerning HIV antenatal care in the UK. Moreover, the chapter will emphasise how this research has created new information about the requirements and contingencies of HIV specialist antenatal care. The chapter will then consider some of the limitations of this study and conclude by suggesting areas of future work.

### **The HIV Diaspora as a Tool**

At the onset, this thesis illustrated how all of the events that took place in the clinic were intimately connected to places and spaces far away from there and to people who occupied or were imagined to occupy those spaces. In this way, the thesis argued that in order to begin to understand the problem of HIV as it became apparent in the clinic, attention must also be paid to the problem of HIV outside of the clinic and the UK.

Accordingly, this thesis has explored how the HIV specialist antenatal clinic — and all of the patients cared for within it — are entangled with geographical spaces that have (or are imagined to have, by the patients and practitioners within the clinic) significantly different ways of approaching HIV than the clinic and the patients and practitioners within it. Thus, I have considered how we could begin to think about and explain the implication of place and space, the effects of the movement of people between spaces, and the significance of the previous spaces that they occupied. Hence, as a consequence of the fact that the majority of the clinic's patients were from countries wherein HIV and death were not decoupled, HIV in the clinic was intricately part of what I have called an HIV diaspora.

As mentioned before, I use this term to articulate the inequalities and differences between the effects HIV has on the lives of HIV-positive women in different geographical locations. In this way, I have argued that the diasporic HIV-positive women involved in this research were simultaneously connected to and affected by the vicissitudes of HIV in multiple geographical locations. In

other words, because the majority of the clinic's patients were immigrants, and while some of them had become British and/or had permanent residency in the UK, they were all perpetually and intricately connected to their countries of origin. Moreover, these connections were always significantly affected and amplified by (various issues related to) the meanings, consequences and effects of HIV (as they were or were imagined by the women and practitioners to be) in their countries of origin *and* in the UK. Thus the concept of an HIV diaspora expanded upon Fassin's argument (2007) that people are restricted by the specific possibilities accorded to them (and the groups they belong to) within a particular geographical location. Moreover, the concept of an HIV diaspora enables a way of assessing the experiences of women located within the diaspora that takes into consideration their complex positionality and the unequal global distribution of ART and advanced HIV care without reducing their experiences to issues related to their "culture" and/or (lack of) access to resources (Nguyen et al., 2011, p. 292). In connection with the above, the HIV diaspora is a valuable conceptual tool that may be used to better understand the contingencies of the experiences of being or caring for (an) HIV-positive (pregnant) mother whose current care location is different to where they came from (and wherein HIV and death may not be decoupled).

Moreover, the concept of an HIV diaspora considers the diasporic significance and effects of (bio)medical technologies. This is important because, as I have made clear, the clinic's patients and practitioners simultaneously contend with the meaning of the technologies on offer to them in the clinic, and in multiple geographical locations. This requires that patient and practitioner consider the possible future consequences of using technologies that promise the prevention of vertical transmission, but may also risk exposing women and their children to the stigmatising effects of HIV. Thus, for women living with HIV located within the HIV diaspora, biomedical technologies and prevention methods have specific meanings and effects for them and their relations because of their incorporation within the diaspora. Moreover, throughout the thesis I have argued that the HIV diaspora is maintained and its boundaries are policed by various technologies such as viral load assays, and by people.

Some of these complexities were explored in Chapter Four where I argued that various ways of understanding HIV may be built into the technologies that the clinic relies on to help prevent vertical transmission. In that chapter I made it clear that the process of assessing a patient's viral load concerned the acquisition and coordination of information, as well as the way in which the practitioners (and their patients) negotiated the various technologies available to the clinic, and the different understandings of HIV that were *built into* and generated by the technologies. In connection to the above, I have further clarified that HIV-positivity is not a requirement in order to be included into the HIV diaspora. Rather, people connected to HIV-positive diasporic women also risked being affected by the diasporas' stigmatising and violent consequences. I will return to this argument later in this chapter.

Thus, Chapter Six considered the way replacement feeding functioned as a "fluid technology" within HIV diasporic communities (de Laet and Mol, 2000). In that chapter, it became clear that women located within the HIV diaspora who replacement-feed their infants may protect them from the *real* of HIV, while simultaneously exposing their offspring and themselves to HIV stigma and discrimination. Moreover, I argued that "HIV stigma" could be used as a tool to control women located within the HIV diaspora and reaffirm their position within their families and communities. Therefore, HIV stigma, or rather the threat of its stigmatising effects, was used as a tool to influence and control women located within the diaspora. Hence, the concept could be of considerable use to the clinic because the HIV diaspora permeated all aspects of care in the clinic. Further to this, the arguments made above are of practical use in the clinic because they encourage consideration of the multiple and fluid meanings various technologies may have to both practitioner and patient because of the HIV diaspora.

## The Requirements of Caring Care

As discussed in Chapter Three, the fieldwork I conducted has enabled me to uncover the logics that were embedded within the practitioners' in the clinic practices (Mol, 2008, p. 8). Thus, influenced by Mol and Law, I have explored some of the ways in which the clinic's patients' HIV was enacted as a result of how the practitioners in the clinic cared for them (Mol and Law, 2004, p. 55). And in doing this, I have investigated the way in which the identity of HIV was maintained in social, clinical and technical areas. Further to this, the thesis has considered what successful specialist HIV antenatal care requires of both practitioners and patient. Therefore, as explained in Chapter Three, like Mol and Law, I explored what HIV, within the context of pregnancy, was for patients and practitioners in the clinic and paid attention to the ways they "intervene[d] into it", "counter act[ed] it", and attempted "not to know it" (Mol and Law, 2004, p. 49).

However, I have also argued that the lives of HIV-positive pregnant women are not only affected by the way in which their HIV was enacted in the clinic, but also by how HIV and the women were perceived and *cared for* or not, outside of the clinic in the present and future. Thus, this thesis has shown that the way patients and practitioners imagined the future mattered in the clinic. It is here that this thesis makes a contribution to STS approaches that consider enactment by clarifying the significance of a patient's unarticulated feelings (Mol, 2008, p. xi). Accordingly, I have made an important distinction between what becomes articulated (and thus made visible to the ethnographer) and that which remains unspoken (at the time of observation), but has the potential to matter in the future.

As I have argued, this is important in the clinic because the practitioners imagine that it is precisely that which they cannot detect (the patients' unspoken feelings) that may entirely disrupt care. In other words, the provision of care from their perspective can be threatened in numerous ways, as described in Chapter Five. However, the practitioners are able to anticipate and attempt to contend with many of these threats because they are aware of

them. But they cannot anticipate the disruptions that a patient may cause unless she somehow “speaks”.

Moreover, the description of HIV specialist antenatal care that I provided in this thesis has made it clear that the patient being “cared for” is not limited to the present-time pregnant patient but encompasses the “future-patient”, her (future) offspring and her (potential future) sexual partners as well. Therefore, from the practitioners’ perspective, the provision of good care, i.e. caring care, does not stop once the patient is discharged from the clinic, nor is care deemed successful after it has been confirmed that her baby was born free of HIV. Thus, importantly, the provision of caring care does not have the successful prevention of vertical transmission as its goal. Instead, the provision of caring care would extend beyond the patient’s virus (as it may or may not be transmitted to her baby) and encompass and (hopefully) affect the patient and everyone (that may become) connected to her *future potential*. Further to this, good care and thus the provision of caring care (from the perspective of the practitioners) entails that they attempt to ensure that the futures they imagine for HIV-positive women and their babies always continue to be possibilities.

The significance of the temporal aspects of care become clear in what I have written above. Accordingly, as mentioned before, the practitioners’ care efforts in the clinic always concern the effects that the work that they do in the present may have in the future and in relation to any number of people. They do not simply try and prevent vertical transmission of HIV. The future potential pertains both to HIV (in its absence or presence) and also to behaviour. For example, the practitioners imagine that the provision of *caring care* could enable patients who had displayed questionable mothering skills to become “good mothers” in the future.

To put it another way, the practitioners know from experience that they are able to do certain things in the present which will prevent vertical transmission, as well as influence *bad* mothers to become *good* and enhance their health. The things that stand in the way of ensuring these futures are the

current patient, her circumstances and the technologies, and sometimes other professionals that the antenatal clinic's practitioners are required to work with. The practices that the HIV specialist practitioners engage with when they attempt to negotiate these obstacles is part of the caring care that they strive to provide.

Throughout this thesis, I have argued that the successful prevention of vertical transmission of HIV requires that the practitioners also use their imagination to predict disruptions to their plans for care. Therefore, the practitioners do much more than facilitate the *connection* between patient and biomedicine and technologies. They are instead absolutely vital to prevention efforts. Here we see the significance of each practitioner's moral, ethical and professional politics. Accordingly, while Geertz has argued for the importance of making the thought processes of researchers visible (2001), I contend that it is equally important for the ethical thought processes of medical practitioners caring for people affected by HIV to be made clear. The need for transparency became especially obvious in this thesis in relation to the discussions on the requirements of good care.

In this way I argued that while good care was something that the practitioners strived to provide, it was not possible for them to establish if good care had actually been delivered. As discussed above, this was because the beneficiaries of good care were (from the practitioners' perspective) people who had not yet come into being (as in they had not yet been conceived or born) or were otherwise unidentifiable to the practitioners (as in present-time patients' (future) sexual partners). In this way, the practitioners did not assume that their patients were in monogamous sexual relationships, nor did they assume that a patient's named sexual partner was necessarily the father of her (unborn) baby. The practitioners' work of discovering these relations and assessing the (legal and moral) risk and responsibility that may be ascribed to them, became part of HIV and the provision of good care in the clinic" (van der Zaag and McKnight, 2016, forthcoming).

## The Consequences of the Generative Capacity of Biomedical Technologies

The discussion above clarified the fact that as soon as a patient discloses her HIV status, HIV will indelibly be connected to her (within her social relations) and her (unborn) baby, even if the baby is born free of the virus. In this way, the *real* of HIV (as it is imagined to exist prior to and independent from biomedical investigation and intervention, as well as the host's body within its social environment: "[A] seemingly stable object" (Rosengarten, 2009, p. 28)), is not limited to the HIV-positive woman's body even if it is not physically transmitted to another body (van der Zaag and McKnight, 2016: forthcoming). Subsequently, I have argued that the various technologies that were used to ensure the prevention of vertical transmission of HIV had the potential to expose the (former) patients and people connected to her, such as her offspring, to *HIV*. Following this, it becomes clear that from the patient's perspective that the requirements and consequences of (successful) HIV antenatal care were at times hugely problematic.

In relation to this, I argued in Chapter Six that replacement feeding may potentially expose HIV-positive women and their babies to HIV while simultaneously promising protection from the virus. While Mol and Law explored the multiple ways in which people with diseases interact with some of the technologies meant for their conditions and how people are required to reorganise their lives as a result of the requirements of the technologies (2004, p. 50). I further their argument by contending that it is not only the necessities of the technologies that are significant but also how the technologies in question are used as HIV detection mechanisms by members of the women's communities, and the way in which the same technologies are also used as HIV prevention technologies in the clinic. Prevention technologies thus simultaneously promise lives less affected by HIV, while at the same time they risk exposing women and their families to other forms of HIV. Thus, there is a caveat attached to all the things that take the future into consideration (here specifically biomedical technologies that are used to prevent vertical transmission of HIV). The caveat is that what they mean or (can) do in the future is multiple. They can, for example, prevent HIV while

also exposing people to it; hence they can protect and also harm. Importantly, the harm that they can cause is specifically related to women who are located within the HIV diaspora.

As mentioned above, I argued in Chapter Four that the logic of care in the clinic necessitated a system that was able to contend with and counteract anyone or anything that was suspected by the practitioners of possibly *doing HIV* in a way that they felt was counterproductive. However, I have also argued that the practitioners are aware that the technologies and practices that they are required to engage with may further distance them from the real of the virus. Moreover, they may also in fact make the practitioners change the real of the virus in a way that will later be discovered to have been counter-productive to their prevention efforts. I considered this in Chapter Four in relation to the viral loads assays used by the clinic.

But here I would like to consider the discussion in relation to the practitioners' feelings about the care they provide. The thesis has considered the way in which biomedicine and biomedical technologies' ability to intervene into vertical transmission of HIV has changed what is at stake for the medical practitioners. In other words, the knowledge that a future free from, or less affected by HIV,<sup>140</sup> is possible for both mother and child, transforms the import of the practitioners' practice in the present. Of course, the complexities that I am describing are entirely related to the fact that it is now possible to cut the risk of vertical transmission of HIV to less than 1% (CDC, 2012, p. 1). Thus, the promise contained within the biomedical technologies on offer in the clinic may simultaneously enable lives less affected by HIV while also placing a tremendous burden on the practitioners. This is because now that the biomedical technologies are understood of as being (almost) infallible, each and every care decision made in regards to a patient is felt by the practitioners to be even more significant.

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<sup>140</sup> The mother will be less affected by HIV, if her baby is born free of HIV.

## **Patient Autonomy and Future Patients**

Throughout the empirical chapters, I have explored whose interests are served by the care provided in the clinic and I have made it clear that the people who are the beneficiaries of care are the imagined future postnatal patients and their (hopefully) HIV-negative bab(ies). Thus, the practitioners do the work that they do in order to facilitate the emergence of an imagined postnatal woman and her baby, (hopefully) born free of HIV. Ultimately, this woman will have been so enhanced by the care that she was provided with during her pregnancy that she will be able to help the practitioners ensure that the virus contained in her body is never transmitted to other bodies in the future, be they sexual partners or her own future offspring. Hence, the care that the practitioners provide patients with is, as mentioned above, ideally meant to also benefit the lives of any number of people who may or may not yet exist or be known to the patient or practitioner.

Thus, in connection to the above, and from the practitioners' perspective the emergence of the imagined future patient and her baby born free of HIV depends on the care provided, and the biomedical technologies available to the clinic and to the patient's behaviour. Importantly, the practitioners imagine, based on their experience, the necessity to anticipate possible technological malfunctioning in order to prevent disruptions to the emergence of the future patient and her baby. As I have argued, the practitioners feel that patients must be encouraged to imagine their futures. However, a problematic result is that what the patients imagine their future to be is understood by the practitioners to also potentially disrupt the provision of care; in other words, to cut the network of care in the clinic. Therefore, as discussed in Chapter Five, from the practitioners' point of view, if the network of care is cut (Strathern, 1996), any number of people (real or imagined) may be affected.

In response to this, the practitioners attempt to sway the way in which the patient thinks about her future and the future of her offspring. An important consequence of this is that the present-time patient cannot be treated as if she were a fully autonomous patient who is adept at making informed

decisions about her care, if and when her desires (are thought to) contradict the practitioners' plans for her care. Consequently, I argued that the most significant care decisions in the clinic are negotiated by the practitioners in *consultation* with a figure that they have imagined. This figure represents the way they envisage the patient and her unborn baby in the future, and the practitioners speak and act on behalf of these future bodies and subjectivities. Hence, the specialist care provided to HIV-positive pregnant women in the clinic is directed towards the near-future patient. Accordingly, good care in the clinic requires that the practitioners ensure that nothing adversely interferes in her (and her babies') enactment, including the present-time pregnant patient.

From the practitioners' perspective, imagination is consequently part of what HIV may become in the clinic. As mentioned before, this supposition is in line with Rosengarten's articulations on the status of the imagination (2009). She contends that imagination is always "present and inherent to what we take to be an external, unmediated "real"" (2009, p. 21). Importantly, however, is the fact that the practitioners would assert that while imagination may become part of HIV in the future, there is nonetheless an "external, unmediated 'real' of HIV" in the present, that is not understood (by the practitioners) as having been affected by imagination in the past or present (2009, p. 21). The concept of an imagined and/or future patient contributes to understandings of antenatal HIV care by acknowledging the role the practitioners' imagination plays in prevention efforts. Moreover, it furthers Mol's argument that the provision of good care does not (necessarily) entail offering patients choice in regards to their care (2008).

Throughout the thesis, I have demonstrated how women incorporated within the HIV diaspora (especially those who are in the UK illegally) are dependent on their families and communities for support. Moreover, the practitioners view the patient's lack of autonomy (as her autonomy pertains to her family and community) as being problematic and a potential threat to their ability to prevent vertical transmission of HIV. This is interesting when thought of in relation to the fact that the practitioners do not care for their patients as if they are autonomous. From their perspective, a patient's autonomy is therefore not

desirable in and of itself. Instead, the value or usefulness of an autonomous individual (be they patient or practitioner) has to do with the things that the person might do with their freedom (here freedom pertains specifically to the ability to make particular decisions about medical care), and the effects those decisions may have on the individual and those connected to her in the future. This belief requires that someone is able to assess and imagine the possible outcomes of a patient's behaviour. In the case of the clinic, the practitioners make these determinations.

Moreover, while a patient may be treated like an autonomous patient during her time in the clinic, this autonomy could be revoked in the future at any time. In other words, autonomy is not a static state that an HIV-positive diasporic woman may or may not inhabit and have access to. Instead it is something that is constantly negotiated, potentially rescinded and/or granted. As a consequence, the previous chapters have shown that patients in the clinic were treated as if they were able to make autonomous decisions about their care if and when their decisions conformed with the practitioners' plans. The practitioners' rationale for these practices is the fact that the patient(s) to whom their care efforts are directed are the future postnatal woman and her baby. If these future patients are able to have the chance of being fully autonomous and also have lives less affected by HIV, the present-time patient cannot be allowed to get in the way of their emergence.

### **Limitations of the Study**

Some of the limitations of this research were discussed in Chapter Three. In addition to the concerns mentioned there it is important to state that the findings of this thesis should be considered with caution. In other words, assumptions should not be made about the experiences of African and black women living with HIV and their care providers in other locations based on my findings. Rather, it is probable that HIV-positive African women and HIV specialist practitioners in other areas of the UK might have very different experiences than the ones described here. Moreover, it is important to

mention that I only spent a short amount of time in the field. It is quite possible that had I spent more time in the clinic and further immersed myself in the field, as is common in a traditional anthropological study, I would have been able to provide a more encompassing analysis of HIV in the clinic. However, despite these limitations, I was able to produce intense and qualitatively valuable data due to the intimate relationships I established with research participants.

### **Future Work**

The work presented in this thesis highlights significant avenues for further research. One of the most pertinent is to further investigate the effects the HIV diaspora may have on both HIV-positive people and on people connected to them. This work could explore how the stigmatising effects of HIV emerge and are used within diasporic communities, and it could attend to the way in which the stigmatising effects of HIV may become disconnected from the material real of HIV. Here I am thinking in particular of the way the children of HIV-positive mothers are subjected to HIV stigmas despite being born free of HIV. In relation to this, additional research could consider the ways engagement with various HIV prevention and/or detection technologies may also expose women living with HIV and people connected to them to HIV related violence and stigma.

Another pertinent area of further research would be to explore in more detail the experiences of the HIV specialist practitioners. This work could include more clinics so that there is less of a risk of individual participants being identified. This would then allow for analysis into the way in which practitioners attempt to protect their patients from people and institutions that they feel may be harmful to their patients' wellbeing. These were significant themes that emerged during my field work but I have chosen not to disseminate the findings in this thesis out of concern over not being able to protect the practitioners' identities, as discussed in Chapter Three.

## Final Thoughts

The lack of privilege granted to diasporic HIV-positive women has been a reoccurring theme throughout this thesis and within the HIV/AIDS pandemic. And, while there is a temporal component to the data in this thesis because it was collected years ago, the arguments I make are still highly relevant today. This becomes evident when we consider the difficulties in eliminating vertical transmission of HIV — an achievement that is technically possible (de Wit, et al., 2011, p. 385; UNAIDS, 2012, p. 43; van der Zaag and McKnight, 2016, forthcoming).

While it is possible to reduce the risk of vertical transmission to less than 1% (and this is undoubtedly an incredible feat for biomedicine) this fact alone does not mean that women living with HIV or their children will not die as a direct result of HIV. This is unconscionable. But we knew this before I began this research. We knew that life, the ability to live free from certain diseases/afflictions, is a privilege that is intricately connected to geographical location. However, this thesis has drawn out how exclusion from privilege *follows* women as they move within the HIV diaspora.

Further to this, this thesis has made it clear that proficient care and the prevention of vertical transmission of HIV should be considered in relation to the fact that it would not in and of itself assure women that they will be able to live with HIV and secure their children's lives. In other words, I argue that there is a danger in singling out the possibility of reducing the HIV transmission risk to less than 1% — and hailing that a success — without also considering what might happen to the people involved after the intervention(s) take place. For instance, what are the life chances of diasporic mothers living with HIV and their children? In other words, the promise of any (bio)medical technology and/or intervention should be considered in relation to the circumstances and expectations, now and in the future, of the people who are meant to benefit from them.

Thus, the provision of good care and the successful prevention of vertical

transmission of HIV is not enough for the clinic's patients. Women living with HIV need more than this; they need to be able to live lives that are not constantly foreshadowed by death. They need to know that their future selves and their future children will have access to the care and biomedical technologies needed to sustain their lives. Further to this, women living with HIV need to be able to protect themselves and their loved ones from the stigmatising effects of HIV.

Accordingly, this thesis has made it clear that women living with HIV who are incorporated into the HIV diaspora depend on their ability to stay in a place wherein ART and appropriate care are available *and* stave off the effects of HIV. This is not an easy task. In conclusion, the care provided in the clinic will always be under threat as long as ART, *safe* ways of replacement feeding, and proficient care are not universally available. To put it another way, good care in the clinic is threatened by the fact that HIV and death are only disassociated in certain global locations. Finally, it's important to note that this thesis has made it clear that the care provided by the specialist practitioners attempts to counteract and anticipate the harmful effects of the HIV diaspora on their patients. This is important work. Making it easier for the practitioners in the clinic to provide care should therefore be of utmost urgency.

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### Application Process Flowchart

■	Process for obtaining ethical approval
■	Site-specific assessment for non-NHS sites
■	R&D Permission for NHS sites
■	Proportionate Review

**For non-NHS sites only: Does your study require site-specific assessment?**

- [Requirements for site-specific assessment](#)
- [Guidance on SSA exemption](#)
- [How to apply for SSA](#)

If yes complete the non-NHS SSI form in [IRAS](#).

- [Submit non-NHS SSI form to local \(or specific\) REC for review](#)

If you consider your study presents no material ethical issues, it may be eligible for review under the proportionate review service

- [Proportionate Review](#)

Develop your study idea

- [Guidance from NHS R&D](#)

• [Is my project research?](#)

• [Requirements for Ethical Approval](#)

**Ensure any external funding is agreed in principle before submitting REC and R&D applications.**

Complete IRAS form and develop supporting documentation

- [IRAS web site](#)
- [Participant Information Sheets and Consent Forms](#)

• [Book in your Application](#) via either the

- [Central Allocation System](#)
- [Local Allocation Service](#)

Submit your application and supporting documentation to the REC allocated to review your study within 4 days of booking.

REC coordinator validates application within 5 working days of receipt. Validation will be confirmed by letter. **60 day clock starts from when a valid application is received.**

You will be invited to [attend the REC meeting](#).

Application reviewed by main REC and the decision of the REC is advised by letter.

Provisional Opinion - further information requested (*clock stops whilst awaiting further info*)

Submit further information for review as requested (*clock restarts when further info received by REC*)

If your response to the REC is incomplete, you may be asked to supply a more detailed response to the initial request for further information but no new issues may be raised by the REC at this stage

What other approval do I need as well or instead?

- [Contact your Trust](#)
- [Other Approvals](#)
- [MHRA](#)

All research involving NHS research sites requires permission for research for each site.

[NHS R&D Forum](#)

Applications deemed invalid may be modified and rebooked.

If your application I deemed not valid but outstanding information appears relatively straightforward, the Coordinator may contact you and request outstanding information before it can be validated.

Submit outstanding information to REC

The REC is committed to returning an opinion within **60 days** of receipt of a Valid application.

No opinion - REC seeks advice from a specialist referee. *60 day clock does not stop while waiting for advice.*

Favourable Opinion with Conditions

Favourable Opinion

Not requiring review by NHS REC

Unfavourable Opinion

- [Appeal](#)

Modify application and [resubmit](#)