Motherhood & Negotiating Social Fields
Experiences of Zimbabwean Women Living with HIV

Clare Spronk-Bailey
AMMA August 2009
Supervisor: Prof Dr Anita Hardon
# Table of Contents

**Acknowledgements**  
iv

**Summary**  
v

**Chapter 1: Introduction**  
*Women’s Bodies*  
p4
*Negotiating Citizenship*  
p8
*Beginnings*  
p12
*Chapter Conclusion*  
p18

**Chapter 2: Diagnosis: A Turning Point**  
*The Women’s Journeys & the Moment of Diagnosis*  
p21
*The Biosocial Field & Access to Biomedicine*  
p31
*Immigration and Leave to Remain*  
p33
*The Decision to Remain & Implications for Motherhood*  
p36
*Chapter Conclusion*  
p38

**Chapter 3: Disclosure: How to tell People that I have HIV**  
*Disclosure*  
p40
*Telling Sexual Partners & Becoming a Mother*  
p46
*Acceptance within the Wider Community*  
p49
*Passing*  
p50
*Chapter Conclusion*  
p51
Chapter 4: Managing Bodies: Being an HIV Positive Mother  p53
Individual Bodies  p53
The Forming & Managing of the Biomedical Self  p54
Motherhood at Stake: Disclosing to Children  p57
Pragmatics of Motherhood  p60
Chapter Conclusion  p61

Chapter 5: Finding Support: Forming Networks  p62
Dialogue about Networks  p62
Forming Novel Relationships  p66
Acquiring Resources  p69
   Acquiring Capital: Becoming Pregnant  p71
   Acquiring Capital: Having a Baby  p74
   Acquiring Capital: Being a Mother  p75
Immigration & Social Capital  p76
Chapter Conclusion  p77

Chapter 6: Conclusion: Moving On  p78
Diagnosis & Management  p78
Finding Support in the Women’s Action Group  p80
Engaging as Citizens  p81
The Future of Biological Citizenship  p83

Appendix  p87
Situating Myself  p87
Some Notes about Methodology  p88
Abbreviations  p94
Transcript Conventions  p94
Bibliography  p95
Acknowledgements

I should like to thank Anita Hardon for her timely and very perceptive comments, which have acted as invaluable signposts throughout the planning and writing of this research. Thank you too to Eileen Moyer who led some of us through an extremely thought provoking course on AIDS in the 21st Century. You helped me to temper some of my political leanings and stay close to the voices of the people on whom I might base my research. Thank you to my companion Pieter-Bas, for joining me on the journey of anthropological discovery over the last twelve months. Thank you for your patience during our mind boggling debates over the dinner table; for your unwavering support, cooking and endless cups of tea, especially during the last couple of months. Thank you mum for those early stories of the Zambian escarpment, they help me to see beyond. I should like to thank Georgina Caswell for putting me in touch with the group of women in this study. Thank you to those at the organisation where I was based for including me in your activities. My greatest thanks go to the women who I have tried to represent faithfully in the following pages. Without you this piece of writing simply would not have come about. You have inspired me by your courage, resilience and determination.
Summary

‘it’s a journey, HIV is a journey, that is how I see it really, it’s a journey, when somebody really smiles about their HIV, they’ve come a long way . . . but the journey is very difficult, it’s very difficult, there are stages, there are very difficult stages’

(Susan)

This qualitative ethnographic research is a story about journeys, about separation and about finding spaces of support and places where women can be heard. It is specifically the story of ten women at a particular moment in their own journey, one that has already been marked by a lot of ‘heart break’ and difficult choices. The women in the study are all connected in some way to a sewing group in London, providing a space of support, raising awareness and advocating for both women who are living with an HIV diagnosis and those who are not. The organisation is concerned with the rights and welfare of women refugees and asylum seekers, students and migrant workers living in London. The women have reached a point in their own journey where they can talk and sometimes laugh about their experiences. As a result this research tells the stories of women who, as Susan put it, have come a long way and can begin to smile. Each story and situation is unique, women are at different points along the way, they have migrated to England at different times and for different reasons, they are at different stages in their life, some are mothers and some are not. Yet what unites them is that they are Zimbabwean, they are women, they are migrants, they have been diagnosed with HIV since their arrival in the UK and shoulder particular expectations because they are women. There are a disproportionately high number of newly diagnosed cases of HIV in the UK amongst people coming from sub-Saharan Africa. Zimbabwe represents a recently arrived group. Women are overrepresented amongst these infections and have become the object of much research. However, there has been very little qualitative research amongst this group. The moment of diagnosis is a turning point for these women and a time of mixed experiences. Entry into the ‘world’ of HIV has
conferred certain benefits, spaces where they can find support, where they can gain knowledge and move on. Simultaneously though they find themselves in an uncertain situation because of their immigration status and this emerges as the most pressing and greatest challenge for the women in this study.

The research also documents my own journey as a medical anthropologist. I had set out with the main question to study the experiences of the journey of becoming a mother and motherhood itself for HIV positive Zimbabwean women living in London. I realised that they would not be living in isolation and perceived that their relationship with society and the wider body politic would be dynamic. I wanted to explore the interface between these encounters and how women negotiate them in order to make sense of their new context. Further, my questions included wanting to understand what motherhood meant to these women and if it was experienced differently in their new context in the UK. How did these meanings influence the way individual women experienced their body and own sense of self? I wanted to know how the social environment in which they lived and found support impacted on the way the women experience having HIV and being or desiring to be a mother. The study was designed to find out how women were supported or not by the social and political body as individuals living with HIV making choices about becoming and being a mother. Finally, how did their sense of ‘body self’ influence their choices to pursue motherhood and motherhood itself and find support as women living with HIV? The theoretical approach traces the individual body as both corporeal and embodied, that is engaging in the social world and being transformed as a result. What emerges is an ambiguous situation, a ‘messy’ citizenship. Women simultaneously inhabit different worlds and find different

---

1 ‘Body Self’ is a term used by Scheper-Hughes and Lock to understand individual lived experience (1998). I replace it in this study with a concept of the individual body as corporeal and embodied that will be explained in the following pages.
ways of identifying themselves within them. They move into one that supports, empowers and gives them a space to exercise their voice and one that threatens to immobilise them. The world that supports them is a social field, a collective of citizens, gathered around the HIV diagnosis, the other is one of uncertainty about their immigration status and the macro influence of the state. There is still another social space of the Zimbabwean community in the UK that represents values from back home. Engaging with these spaces influences their experiences as women seeking to fulfil the role of motherhood. Experiences in the biosocial field may even influence access into national citizenship. What is constant throughout these experiences is that motherhood persists in the new context as a crucial role for a woman. It is in fact the way to prove ones womanhood. I shall explore how women can fulfil this role and survive socially in the face of challenges presented by being a migrant and having an HIV positive diagnosis.
Chapter 1: Introduction

‘Was that a place where you could find support?’ I said, referring to the group.

‘Yeah, because they are people who you will talk, they are people who you are on the same page-‘ I probed Sandy to explain, ‘In which way?’

‘In that it is African women, so we kind of have similar things that we are going through, the er, [immigration] status issues, er the being positive, our general customs and everything, it’s like ok, we’re speaking on the same page, it’s different if, not being racist or anything, speaking to a positive English woman, that’s different because we have, our customs are different, it’s like yeah we are talking about the same thing, we are both women we are both positive but there’s certain things that us as Africans, is expected of an African woman which is not really imposed on the English custom.’

‘Can you give me an example?’ I said, wanting to understand more. Sandy replied,

‘OK [laughs] well first of all is like being a mother . . . That is literally a yes, that’s a must, where as in the English custom it’s not as much. It’s not like a must, everybody has to, be a mother to prove that they are a real woman. Whereas in African community, the Zimbabwean custom, that’s how you prove you are a real woman, being a mother when you get married’,

(Sandy)

I had taken a train across London to meet Sandy, it was a dreary, rainy day, she met me at the station and we went to her flat, sparse, well ordered and cared for. A large television dominated the room and it was blaring out daytime TV as we arrived, she had obviously left in a hurry to meet me. She had recently been rehoused by social services and was waiting to hear from her consultant, a woman with whom she has a good relationship, as to whether she would be starting anti-retrovirals the following week. We drank tea, rooibos for her and black for me with boiled condensed milk. We discussed tea and how making it to suit people’s tastes could be so difficult, which she felt was especially challenging in England. She is connected with the Women’s Action Group where I was based and had found great support there and was now engaging in advocating for and supporting other women living with HIV. She is especially motivated to support young people within the Zimbabwean community in the UK living with HIV, either living with a diagnosis themselves or having parents who have HIV. In
her mid thirties she was not a mother and felt very free to make a choice about it, mainly she said because of the way that she had been brought up by her parents to make her own choices. Yet despite this relative freedom to choose she still felt the ‘pressure’ of the expectation that she would one day have her own children, even if it was just one. When I asked her about that she told me that this sense of pressure came from within the Zimbabwean community both in the UK and back ‘home’ in Zimbabwe. She had considered adoption but people from within the community would say ‘oh no you can’t, you have to have your own, even if it’s just one, then you can adopt’. She was one of the ten women in this research whom I interviewed in depth and followed in their group activities. Although the group is varied in many respects, such as in age and time since diagnosis, the way they have experienced family and the support they have received from them, Sandy represented sentiments that most of the women vocalised in their own interviews and focus group discussions and the ‘informal’ time that we spent together. She identified herself as a Zimbabwean woman and she found support in the group because they shared issues of insecure immigration status, being HIV positive and sharing ‘general customs’. She made clear to me that a key concern for women is the expectation that as women they would become mothers, something that was intimately linked with their value as a woman. These things were what united the women whom I spoke to. It is clear that their own sense of who they are is being transformed as they participate in new social contexts. The values from Zimbabwe, a place they refer to as ‘home’, are very present in the new context. It is often within the context of the Zimbabwean community in the UK that they must ‘prove’ their womanhood and survive socially. What is at stake for these women is surviving, living well, keeping healthy, finding independence and moving on. I was able to talk with women who were comfortable to share some of their experiences with me, we could talk openly to a greater or lesser extent but certainly all were very open within a safe environment. They had had very difficult journeys and they expressed a real
sense of hope for the future but this was a hope that was tempered by what I often perceived as an underlying uncertainty and anxiety.

The research is essentially about the individual experiences, amongst Zimbabwean women living with HIV in London, of being and becoming a mother. The research traces part of their journey and considers their movement to a new place both physically and symbolically. The women have journeyed to a new context from an area of very high HIV prevalence and are engaging and participating in a new social space. They have all received a positive HIV diagnosis since their arrival in the UK. As a result they have had a very tangible experience of their own material, corporeal body, one that is kept alive by medicine but also one that bears the experience of social meaning attached to the female body with HIV. What emerges through the stories of these women is that through their individual bodies, infected with HIV, they are engaging in networks and building social relations that are paramount for their survival as women living with HIV and negotiating motherhood in a new context. Being able to be accepted as ‘normal’ outside the support systems, partly by being able to fulfil the role of motherhood, is paramount to social survival. It is the idea of a new social field that I shall develop throughout the thesis using an idea from Bourdieu; although he considers a very different context of social class it is helpful as a theoretical approach to visualise the social space and the individuals that populate it (1999). Specifically, I focus on the social field of the HIV network including biomedicine and support groups, which is populated with HIV positive female biological citizens. With the body at the centre of analysis there

---

2 Shilling’s conception of the individual body is useful, he perceives it as an ‘unfinished biological and social phenomenon which is transformed, within certain limits, as a result of its entry into and participation in society’ is useful for my analysis (1993:12).

3 Social Field: ‘a multi-dimensional space of positions. . . agents are distributed within it according to the overall volume of capital that they possess and according to the composition of capital that they have’ (Bourdieu, 1985:724).
is the possibility to consider ‘culture, self and experience’ in a different way (Csordas, 2003:4).

**Women’s Bodies**

The experience of the individual female body is firmly at the centre of this research. I attempt to explore how the body is ‘corporeal’ and as such forms the basis for and shaping of social relations (Shilling, 1993). The concept of embodiment is part of this conception of the body which, whilst material and fleshy, experiencing HIV, is perceiving, present and engaging in the world (Csordas, 2003). An interpretive medical anthropology considers that illness is a lived experience and situated within a social context. Meanings and experiences of illness are linked to cultural values (Good, 1994). Lived experience is necessarily embodied since we all possess bodies and history and social relations leave their traces in the body (Good, 1994). Drawing on the current debate about the place of the body in anthropological research, I conceive of the women’s body as both a biological and social phenomenon, unfinished, it is transformed, by its engagement with society in the new context\(^4\) (Shilling, 1993).

Much writing has discussed how HIV is ‘incrimed’ on the women’s body and renders them subject to social discourses (Lawless et al, 1996). Whilst this remains true to an extent in the lives of these ten women it does not explain their entire experience. They are not left without their own tools and means of engaging in the world. My theoretical gaze on the individual and social body enables us to conceive of a much more dynamic scenario. I argue too that the ‘symbolically valued body’ of a Zimbabwean woman is as mother (Shilling, 1993). The social construction of motherhood amongst African women living with HIV in London has been recognised as a ‘major defining feature of adult life’ by other researchers (Doyal & Anderson, 2005: 1732). Sandy was not the

---

\(^4\) Bourdieu has discussed the body as a bearer of symbolic value and considers the ‘unfinished-ness’ of the body (Shilling, 1993).
only one to tell me that in order to prove your womanhood as a Zimbabwean you have to be a mother. I argue that it is important to understand that it has been within the context of a history of gender domination\(^5\) in Zimbabwe that this ‘symbolically valued body’ of a woman as mother has been established. As such the women’s body needs to be understood within the context of such domination.

My first meeting with some of the women as a group was a cooking afternoon. It became very apparent during this session, whilst huddled together in a tiny church kitchen, waiting for the Thai curry paste to fry, that they had all experienced gender domination in a very tangible way. As the conversation unfolded they told stories, finding recognition from each other about their experiences. They discussed things that were repeated later in the stories that I heard in the interviews and at subsequent gatherings. It was a gender domination felt most acutely by the older women in the study, women who had been married and experienced a lot of ‘heart break’. On this particular occasion as we waited in the small kitchen, we started talking about the pounding of maize back in Zimbabwe. Susan and Patricia started acting it out showing how they would pound the maize in pairs and sometimes with three women, playing games, throwing the large wooden pestle to each other and singing as they worked. Then it began, one woman said that the husbands would just watch and expect to be given food, then they would go to the pub and come back ‘smelly and drunk’ expecting to be fed more food and time in the matrimonial bed. Two other women joined in and lamented about these ways. They told me that these attitudes were based on kinship relations and the patrilineal line. Patricia said disdainfully that you had to sleep with your husband ‘because of the skinny ox that had been given to his family’. They talked about how

\(^5\) Bourdieu & Waquant use gender domination as the paradigmatic example of a form of violence they call symbolic violence (2004).
mothers-in-law ‘were the worst’ in the kinship strata. There was so much competition with them as daughters-in-law, they said and they would want to be involved in every decision. One woman described how her husband had asked her to give some money to his father once. She had signed one of his cheques, absolutely not done in the community in which they were living at the time back in Zimbabwe. She became the topic of gossip of the entire town. She was incredulous as she described it. The women asked each other ‘why is it that it is men who always make the decisions?’ Susan interjected that so many women are being beaten in their homes in Zimbabwe by their husbands and if you go to the police they say ‘what do you expect?’ and they don’t do anything about it. The policemen say that the husbands do it to discipline their wives because they love them. I suppose they were describing to me what they had experienced in their own situation as the ‘order of things’.

Patricia said ‘we have been liberated here, the UK is so liberal and especially the African woman is liberated by being here’. These kinship ‘rules’ had impacted the lives of some of the women and their children. Grace, a forgiving and gentle woman, described how her husband had died, leaving her with seven children. She was expected to remarry one of his family members but refused and as a result lost everything. She said,

‘so if you refuse they chuck you out of the house, then they take everything. So they took everything, I just came out with my fam-, I had to run away with my children,’

These ideas of gender roles became a frequent topic of conversation between Patricia and me and she told me that when she had first arrived in the UK, staying with her sister who had been here for some time, she would automatically get up very early and start cleaning the house. Her sister asked her why she was doing that and that she didn’t need to do it anymore now that

---

6 Symbolic violence and thus gender domination has been described as ‘the order of things’, made possible by the ‘work of socialisation’ and an established habitus (Bourdieu & Waquant, 2004).
she was living in the UK. Patricia laughed, almost chastising herself for how she had behaved in those early days.

Motherhood is a deeply important role for these women, it needs to be understood in the context of gender domination and is a role that has to be undertaken in order to prove that she is a real woman. It persists as a crucial role and even in a situation of more equality the women in this study pursue it. However, ‘woman as mother’ becomes problematic as the only symbolically valued body when the women are faced with the challenges of the new context. Much of the research on the experience of motherhood comes from a feminist perspective that considers it as a burden to women (Rich, 1979; Oakley, 1979). However, there seems to be a certain lack of fit between the voices of the women that I have heard and this literature. Liamputtong has argued that current ‘social constructions of motherhood do not reflect the realities of non-Western mothers’ in an ethnographic study on South East Asian migrant women in Australia (2006: 27). It is thus important to understand the voices of the women and how they consider motherhood themselves. One educated Zimbabwean woman that I spoke to had observed from colleagues at her work place that English people prefer to have pets instead of children. Despite this impression that motherhood is not as important for British women, many still choose to pursue it in the UK. In the biomedical age of choice and technology, this can be seen by the number of women choosing IVF. During the focus group discussions (FGDs), the conversations about the meaning of motherhood echoed those that I had within the interviews. Some of the thoughts about the traditional role of the mother included, mother as ‘role model’, ‘pillar’ of the family, ‘guide’ to the children, ‘backbone of the family’ and they all agreed that she was the centre of all other relationships. She was a provider of care to her children and sometimes a financial provider. Furthermore, motherhood was
more than just giving birth to a child. It was a collective activity where a child belongs to the whole community. Constance said,

‘being a mother in Zimbabwe you are not just a mother to your own children you are a mother to the society, you are a mother to the nation you know to other children, to other people’s children, to other relatives, extended family, you know’

With this in mind the implications for a mother in Zimbabwe living with HIV are significant, not only because of issues with medication and transmission from mother to child but also the value of the woman. Within the history of gender inequality it is often the woman who receives blame. This is no different in the context of HIV and I frequently heard that AIDS is so often a moral issue within the Zimbabwean community and it is the woman who receives the blame. We will explore this more deeply in Chapter three on disclosure. I argue that these things have been ‘embodied’. The context of gender inequality that has often blamed women, especially those with HIV labels them as immoral. Even when women have acquired alternative explanations for transmission, these values persist and their presence is born out in the difficulty the women have in disclosing their HIV status.

**Negotiating Citizenship**

Following this theoretical gaze on the individual and social body, the individual engaging in society, I argue that the woman’s body as mother is a deeply rooted value that persists in the new context. However, on entering a new context and receiving a positive HIV diagnosis, there are a myriad of decisions, processes and challenges that must be met in order to fulfil the role, whether already a mother or desiring to be one in the future. This will be discussed in Chapter two and later in Chapter four. As such, the symbolically valued woman’s body as mother is problematic. The woman’s body must find her place in the new context. Throughout the thesis, I will discuss the concept of citizenship, one
that the women pursue, trying to find their place in society, a journey that produces ambivalence\textsuperscript{7}. Finding their place and negotiating their position as a citizen is central to the women’s experiences and what influences their consequent experiences and choices about being and becoming mothers. I conceive of the social world, that the women are engaging within, in the way that Bourdieu describes the social space as being a social field (1985). The field is a multi-dimensional space and agents are distributed within the field according to the amount and composition of capital they possess, they engage in symbolic struggles as they use their power to represent the social field and their own social identity (Bourdieu, 1985)\textsuperscript{8}. Different social fields have different qualities and the agents or citizens possess different measures of power. I have discussed that the women enter a new social field on receiving a positive HIV diagnosis, one that supports them. I visualise this primarily as a biosocial one, a grouping or collective gathered around ‘a biological conception of a shared identity’ and made up of biological citizens (Rose & Novas, 2005: 442). This new kind of citizenship is taking place within the context of biomedicine where new ways of perceiving self and each other and what it is to be human are being conceived of (Rose & Novas, 2005). All of the women have entered this field through the National Health Service (NHS) when they received a positive HIV diagnosis. As documented migrants, refugees and asylum seekers in the UK, the women taking part in my study were entitled to free medical treatment in the National Health System (NHS) and limited social welfare benefits (Ndirangu & Evans, 2009). The NHS operates within the principle that anybody should be able to access medical care at the point of need, a principle that formed the foundation of its inception in 1948. As such even if there is ambiguity about a person’s immigration status, they will receive medical treatment, which includes the very

\textsuperscript{7} Novas and Rose have described a number of ‘citizenship projects’ and define them as the ways in which authorities think about individuals as potential citizens and act upon them (2005).

\textsuperscript{8} Bourdieu discusses that ‘what is at stake (in the social field) is the very representation of the social world’ (Bourdieu, 1985: 723).
expensive drugs. If asylum is rejected individuals face deportation and the threat of the discontinuation of life saving treatment. Having entered the biomedical system women enter the world of support groups, the Women’s Action Group being part of this biosocial field. I perceive that the women’s entrance into the Women’s Action Group confers possibilities for them to gain resources. That might be gaining their own status or power within the group as someone who takes on certain tasks or becomes a ‘leader’. With these different qualities, the women make decisions in different ways to get access to knowledge about their HIV diagnosis and rights as migrant women living with it. As the women develop new understanding of their own body with the new knowledge, these resources can be converted into other benefits such as access to more information, support or even resources to support their immigration claims. The biosocial space then comprises members, possessing a form of agency, who are actively involved in shaping the way they understand themselves and relate to themselves as well as to others (Rose & Novas, 2005). Entrance into the new social field, the biosocial grouping, a choice that is not easy to take, confers benefits on the women and brings with it ‘new subjectivities, new politics (and) new ethics’ (Rose & Novas, 2005:458). The benefits are life itself, knowledge and other forms of capital. It is also a place where the traditional role of a woman and the way of being a mother, that the women I spoke to are used to, are discussed as they become challenged in the new context. However, simultaneously there is the uncertainty about whether they will be accepted as national citizens, as documented migrants and recognised citizens in the UK, which poses the most pressing challenge to the individual. Whilst the women identify themselves very much as Zimbabwean and most would one day like to

---

9 Shilling has described these resources in terms of ‘capital’, in examining the body as a form of physical capital, he says that it becomes a possessor of ‘power, status and distinctive symbolic form’ (1993: 127). This physical capital can be converted into economic, cultural and social capital (Shilling, 1993). Bourdieu would call these women ‘agents’ within the social field (1985).

10 Although individuals are technically ‘subjects’ of the crown in England, citizenship is a well understood concept and used to describe how individuals are perceived and governed.
return, being able to stay in the UK is crucial for their survival. By virtue of being economic and political migrants and the emerging ethical debate amongst biological citizens, they challenge the ‘capacity of the state to delimit citizens in terms of place of birth, lineage or race’ (Rose & Novas, 2005:440). The uncertainty surrounding immigration influences how the individuals in this study can fulfil their roles as women and mothers in the new context. Most of the women that I talked with have had to wait for years just to hear if they can stay in the country. Meanwhile, they are unable to work and have no freedom to travel to see their children who may still be in Zimbabwe or South Africa or elsewhere. They may be moved from house to house by social services and some have feared deportation and all the while have been trying to keep healthy. Regardless of whether the women are already mothers or not, I argue that their experience hinges on this immigration status. What is at stake is whether they can make decisions to move on in their life and fulfil the role of a woman.

I argue that as women enter the journey of living with HIV in a new setting, it is only through support that they can survive, support that is found largely within the biosocial field. In the support group they develop a kind of citizenship that challenges the state about how they are perceived as migrant women (Rose & Novas, 2005). Bodies acquire physical capital when they are diagnosed and begin treatment, marking their entry into the biosocial filed. By forming networks of support, by ‘engaging’ and gaining ‘knowledge’, the women find new meanings to their body and acquire social capital and cultural capital respectively with some possibilities for economic capital (Shilling, 1993). The support network, as part of the biosocial field forges its own identity and that of its members, developing new meanings for the body. The groups and their

---

11 Landzelius recognises the pressing political debates regarding health matters and the relationship between citizen and governance when considering the concept of patienthood and emerging health related activism (2006).
active citizens in fact become ‘body experts’ that are involved in ‘educating bodies and labelling as legitimate or deviant particular ways of managing and experiencing bodies’ (Shilling, 1993:145). As a result there is a ‘new politics of personal empowerment and emancipation’, which brings about a discourse amongst the women of rights and shifting power relations that challenges the status quo (Turner, 2003:28). This movement will be discussed in Chapter five. Although expressing a slightly less ‘embodied’ view than I hope to convey, Turner has argued, the ‘body’ becomes ‘an agent that produces discourses as well as receiving them’ (Turner, 2003:46). An ‘agency’ that these women have demonstrated by engaging in the biosocial field at different levels, including the political level in UK and Zimbabwe. In many ways the women that I spoke to are the ‘body experts’. They are the ones who have journeyed quite a distance to be able to talk about their experiences and have formed networks and received support as women living with HIV. They have acquired knowledge about their biology and are ready to support others, lobby for rights and take hold of the opportunities that biological citizenship is opening up.

**Beginnings**

Out of the history of gender domination emerges a discourse of women’s rights, something that the organisation, in which the Women’s Action Group is situated, firmly believes in. More broadly, there was a human rights discourse that was somehow tangible in part of the Zimbabwean community that I met, with regard to the current political situation there. Nearing the end of the field work I was sitting on the tube with Giftie. Morgan Tsvangirai, the Zimbabwean Prime Minister, would be in London addressing the Diaspora the following day. Some of us were planning to go. She was filling me in on what she anticipated he would be saying to the Zimbabwean community as he addressed them in Southwark Cathedral. The Anglican Cathedral Church, a beautiful building in SE London on the banks of the River Thames, has a history of offering hospitality
to many different kinds of people with different causes. She told me that he would be telling the Zimbabwean community to prepare to come home and that things were getting better in Zimbabwe. She was obviously sceptical about the promise of improvements. She told me that only a few days earlier some women from a group called Women of Zimbabwe Arise (WOZA) had been beaten whilst campaigning in Bulawayo, the second city of the country. She proved to be spot on with her prediction. After the Prime Minister had attempted to address the group of a thousand of us, Zimbabweans and sympathisers, standing in the packed nave of the cathedral, one woman responded to his call that ‘Zimbabweans must come home’. She made her way to the front and asked why, since the forming of the new unity government, human rights activists were still being persecuted. His answer was lost amid the jeers and heckling of the gathered throng and he made an early exit from the pulpit. I was curious as to how the prime Minister might have taken this bold question from a woman and Patricia later said that such a thing would be unheard of in Zimbabwe.

In 2003 a small number of women started to hear many stories within the Zimbabwean community in the UK from some of their counterparts experiencing difficulty. As I talked to one of the women founders of the Women’s Action Group, who had observed these things, she spoke of difficulties around domestic violence, child care and HIV and echoed some of the things that I had heard in the church hall. She said that back then there were several deaths, which were quite alarming and traumatic. She told me,

‘what we found out was that there had been a gender dimension to the migration from Zimbabwe to the UK, that more women had come, erm, a lot of them came as professionals but you also have those who came as erm, sort of erm, economic refugees if you like, migrant workers, erm but also what happened was those who came with their families, meaning with their husbands, they found that their roles within the home kind of changed, the power dynamics within the home changed, ah, in that the UK tends to offer women a more sympathetic environment than to men and more so to black men,
so black women tend to do better, you know they really er, obviously still struggle but they do better than their male counterparts’.

She observed that the domestic violence had sprung from a shift in these power relations within families, where the woman was able to exert more influence in the new context and the man’s traditional role was not accommodated. One example that she gave me was of a woman who had come to the UK with her young son leaving her abusive husband back in Zimbabwe. He had subsequently followed her to the UK and the domestic violence re started. One day when she had walked her son to school, having separated from this man, he followed and abducted her. She was violently abused and killed by her husband. People were not coping with the shifts in power, relationships were breaking up and the migration experience was proving to be very traumatic. Furthermore, the normal support networks that existed at home had been removed. Extended family was not there and often people did not know their neighbours, who would usually be on hand to look after the children at a moment’s notice. Sometimes this resulted in women leaving young children at home on their own while they would go to work, cases that would be observed by neighbours and reported to social services, sometimes resulting in children being taken into care. This lack of support by the immediate social environment was a theme that I heard time and again from the women and something that was a real concern to them. She went on to tell me about the emerging issue of HIV in the community.

“At that time, we were also observing a trend whereby there was a very high level of HIV in the community and erm, at that time also Zimbabwe, amongst African communities, had the highest prevalence, and erm because of the stigma attached to it but also denial and the like, people were presenting late so people were dying, again there wasn’t an organisation that was there to actually advocate on their behalf but also to raise awareness, you know, addressing erm, these issues in a culturally sensitive or a linguistically sensitive way so that they would understand, yah so in a nutshell that’s what caused us to set up the network’
There are disproportionately high numbers of newly diagnosed cases of HIV in the UK amongst people originating from countries experiencing a generalised epidemic (Prost et al, 2007). In 2004, Africans represented 32% of new HIV infections in the UK (Hammers et al, 2006). Zimbabweans were amongst them as one of the most recent migrant groups (Prost et al, 2007). Furthermore, there was a reported over representation of new infections amongst African women in Western Europe (Prost et al, 2007). This trend was reflected in the UK where, among attendees at London Genitourinary clinics, 7.7% of African born women had HIV compared with 0.2% of UK born women (Doyal & Anderson, 2003). These findings presented a perceived problem and had motivated me to pursue this current research forming part of the justification for the study. I was especially interested because there has been very little qualitative research done on the lived experience of individuals and no research exclusively amongst Zimbabwean women living in London. There has been some attention to call for an alternative way to approach these issues in research.

The women in this study have migrated from an area of very high HIV prevalence. Taking UNAIDS figures as a general picture, the prevalence of HIV in Zimbabwe in 2006 was reported to be 18% amongst women attending antenatal clinics between the ages of 15 and 49 years old (UNAIDS, 2007). In 2002 the prevalence was reported to be 26% in the same group (ibid). Those who started the Women’s Action Group identified the need for a ‘culturally sensitive’ approach to offering support, one that Prost et al have recognised as very important in addressing these developments in the pattern of HIV in the UK (2007). I was particularly interested in the ideas of motherhood, something I perceived to be an important part of being a Zimbabwean woman. The Women’s Action Group had been started to create a space to help Zimbabwean women integrate into the wider community and navigate the new system. They had wanted to advocate for the women and raise awareness about HIV,
providing a safe place for them to share experiences. However, there was more. At its inception there was a clear desire to be able to network with other organisations, engage with and find solutions for the emerging social issues. The woman who was part of its inception told me,

‘s it was about promoting the positive things of Zimbabwe, ensuring that their contributions were acknowledged and to leverage the other social issues that were emerging such as asylum, refugee issues . so it was a really big agenda for us at that time but the problems of the community were huge’

Through engaging with the biosocial issues they hoped to exert ‘leverage’ on the social issues that were emerging. They also called upon a history of an emerging women’s rights discourse in Zimbabwe and acknowledged the need to form wider networks in order to be strengthened for their cause. The same woman told me,

‘in fact coming from Zimbabwe we had a very well developed civil society anyway where women had been to Beijing12 and everybody knows about the MDGs, women’s rights and all that, so we kind of understand those structures, in fact in order to kind of advocate effectively we need alliances,’

We discussed the issue of motherhood and she elaborated on the theme that Sandy had discussed with me as a way of proving ones womanhood. She discussed the way that women were brought up to expect certain things in life13. She introduced the idea that women may in fact be put at risk to being in abusive relationships because of the strong desire to be married and become a mother. Later as we spoke she said that she had observed in Zimbabwe that most women were put at risk for HIV for similar reasons.

‘it’s also the way we are socialised, we are brought up to expect that eventually one will get married and have children, if you don’t get married at least be a mother, (we are all brought up) with that expectation within the community, you know you cannot be a

12 The Fourth World Conference on Women: action for equality, development and peace held in Beijing, September 1995.
13 Bourdieu and Wacquant call this the ‘work of socialisation’ that produces a habitus for women as mothers (2004: 273).
complete woman and not be a mother, this is what exposes certain women to domestic violence, they want to be Mrs so and so they want to be a married woman, they want to be married to somebody, so we were running an empowerment group saying ‘you are complete if you are on your own’ . . culture is very strong and belonging and wanting to be accepted, very strong, everyone wants to be married, (women) will end up in an abusive relationship or a relationship purely because they want to fulfil that motherhood role, that is expected of you’

Of the few qualitative studies on the experiences of migrant women from sub-Saharan Africa living with HIV in London, Doyal and Anderson draw attention to the importance of the role of motherhood and how it influences the experiences of these individuals (2005). It was this that inspired me to dig a little deeper and understand the specific experiences of motherhood that Zimbabwean women living with HIV had. What did motherhood mean to them and did they face the same moral anxiety that Doyal and Anderson had discussed because of the meanings attached to HIV (2005)? Although not a feature of my discussions with the ten women in the study, the Women’s Action Group had run ‘empowerment’ courses saying that you can be complete as a woman without children and in a sense were trying to offer an alternative ‘symbolically valued body’. The naming of the group tells its own story of its members forging their own identity. Since its inception six years ago I heard that the name has been contested. Being named a straight forward ‘support group’ was rejected perhaps because the women wanted their own strength to be acknowledged. Being known by some of the activities that it does as a ‘sewing group’ was insufficient in describing their vision. Most recently they have settled on calling themselves ‘Harambe: Women’s Action Group’. Harambe is a Swahili word that can be understood as ‘let’s pull together’ or ‘working together in unity’. With active women firmly at the centre of the group, the current name seems to capture the essence of what I had understood as a vision to work together to empower other women to form networks and relationships that enabled them to move on.
**Chapter Conclusion**

The women in this study share an identity as Zimbabwean and have in common the uncertainties of immigration, a positive HIV diagnosis and the expectation that they will fulfil the role of mother. In regarding the experiences of the women as embodied, I have discussed ways of perceiving women’s individual bodies that have historically been subject to blame and gender domination. Motherhood persists as a crucial role for women. Being able to be accepted as ‘normal’ outside the support systems, partly by being able to fulfil the role of motherhood, is paramount to social survival. The individual body and how it engages in society is the focus of the empirical research. What emerges is that the individual finds recognition and a sense of who they are within the context of the social body. They are citizens or agents populating a social field. The social fields are fragmented, the biosocial field being constructed as one that intends to empower and support its members. They struggle to find themselves a place as a national citizen by negotiating immigration procedures, where they demand rights to continued health care and dignity. These fields do not account for their total engagement in the world and represent part of their experiences but nevertheless account for the focus of this research. The future of the group will lie in the pursuit of choices for women and in the group’s ability to develop new meanings for the symbolically valued body, what Mathews has called the ‘cultural work’ of the support group (2000) and Farmer has referred to as new ‘cultural models’ (1994). They will most likely pursue the women’s rights discourse to make choices available about sexual and reproductive health. I already detected these ‘new’ ways of perceiving and being amongst the younger women in the study. The Women’s Action Group intends to offer a place where these experiences can be shared and contested; far from being subjects of power the women pursue ways to discover their own.
Chapter 2: Diagnosis: A Turning Point

‘Motherhood is about SACRIFICE you know, I sacrifice to stay over [in the UK], just to live for them [my children], otherwise I would have gone back to Zimbabwe and I was, I had these two, ah, big oranges in my hands, yeah?’

Patricia gestured as if she was holding a large orange in each hand and looked at them talking as if she had two things to choose from. She explained what she perceived to be her first option,

‘Go back to Zimbabwe, you die and leave them [my children] but it will be good for me because I’ll be gone, no more worries [laughs] wherever I’m going, heaven or wherever but I’ll be done, yeah? Or, I mean, when I go back also the other thing, the other advantage was that I was going to sustain my marriage, em? Be with my husband, still holding that name, Mrs so and so, you know it’s for me, not for my kids, no, for me, I’m Mrs so and so, ‘she is with her husband, she is in her house’, you know all that, and then she died’ She was explaining to me that there would be no speculation about how she died if she went back home. Patricia then explained the second option that she perceived was open to her,

‘Or, I would live then obviously he is going to get married, he is gone, I’d rather lose him, let him go, I’d rather lose everything that I worked for while I was here, let it go, I would rather stay so that I see and live and see my children grow.’

(Patricia)

I had met Patricia a week earlier and we had talked for a long time about many things, the Zimbabwean community in London and a bit about her own story. She had also been present at the cooking group. She was diagnosed five years ago having become sick whilst visiting her sister in the UK. She was admitted to hospital and diagnosed with TB and spent many weeks having treatment. As she was regaining strength she received her HIV diagnosis in the hospital. It was a shock for her and there was a time when she felt like ending her life but there was also some sense of relief since the diagnosis explained why she had been feeling unwell for so long. Earlier in the conversation she had said that she had felt ‘very vulnerable and useless’ when she first received her diagnosis. She had anticipated that people would be talking about her and the inevitable stigma. She described what stigma meant to her and I detected something of the blame and gender issues that I had been hearing from the women.
‘obviously because I travelled all the way from Zimbabwe to England, they would think, ‘she’s been promiscuous in England, she’s been chasing about men because there’s no one controlling her,’”

She had been shocked on receiving her diagnosis because of the way she understood the transmission of HIV,

‘that was the obvious thing people would think about, you know and no one thought about, oh maybe she could have got it from Zimbabwe, not even one because they think if you are married you are in your house you are with your husband, you have got your children and you are going to church, you are a church leader, you know you can’t get HIV, that’s what I thought too, then when I got that diagnosis I even thought, how come? I’ve been going to church, I’ve been a leader in the church, I’ve been loyal to my marriage sixteen years, huh?’

At this crucial moment she was faced with a choice, staying in the UK without her children and beginning the medication that was offered to her, with the promise of keeping her alive or going back home to die but with her reputation intact. She would still hold the status of what was expected of her of being a good wife and mother. Central to her decision to stay in the UK were her three children back in Zimbabwe and the desire to stay alive for them. It was evident as I got to know her that her children were and still are her primary motivation in all that she does. She had to take a lot of medication in the beginning because of the TB and she told me that despite finding it ‘horrible’ to swallow only two pain killers she took those twenty two tablets daily just for her children, to see them grow. She told me proudly that she had never missed a dose. More than that as she said, it was her role and duty as a mother to carry on for them and she had hopes and aspirations for their lives. As soon as she made this decision to stay she was admitted to the biosocial world and the process of her becoming a biological citizen began (Rose & Novas, 2005). At this same moment she began the struggle to acquire ‘national citizenship’. She was allocated a social worker as part of her discharge package from the hospital and started to make an application to the Home Office. It was five years after her diagnosis that she
received indefinite leave to remain in the UK, during which time she had to report every month to the office and was not able to work or travel of course.

**The Women’s Journeys & the Moment of Diagnosis**

The other nine women faced similarly difficult choices and began an arduous journey when they discovered their HIV status. When I first met Susan, a woman in her late forties, she arrived at our appointment on time and wet from the rain. She was visibly shaking and clearly distressed. She explained that she had just been to collect her weekly allowance of £60 but her number had changed and they couldn’t find her records. She had been terrified. She depended on this weekly income to support herself and her daughter, telling me later that her greatest challenge was financial, especially in supporting a growing girl who made many demands on her purse. She arrived in the UK in 2002, initially with a two month visitor’s visa. She had left Zimbabwe before taking up a position as head teacher of a school because she had been frightened by things that she had heard. She described to me that as she was completing a tour of the school after her interview, another teacher had whispered to her to be careful because the previous head master had been killed by Zanu-PF, the ruling party at the time. She didn’t know the details but told me that not being ‘politically active’ and a woman, she didn’t know how to handle the situation and had left Zimbabwe as a result. Susan managed to acquire a student visa before the visitor’s visa ran out, which she renewed three times. In 2005 she had gone to see her GP because she was worried about a persistent rash that she hadn’t been able to shake off over the last five years. The GP chastised her for asking about whether she might have HIV, challenging her that if she hadn’t been promiscuous, why would she even consider it? Susan had a blood test and seven days later received a positive diagnosis. She told me how she sat in front of the GP and heard a long list of results that were all negative, her hopes rose and she began to relax feeling that everything must be ok. The last result was the positive HIV diagnosis. Susan
told me that at that point she just began to cry. She had always been strong and never cried, even when she went through a painful divorce but this was the ‘last straw’. She was angry, towards her mother, towards God, whom she had always believed in and her former husband. It was this anger that had built up after her divorce that seemed to well up inside her at this moment of diagnosis. It was against a man who hadn’t appreciated her and had even mocked her for being a virgin when they married. She had felt betrayed and wondered why she, having never been promiscuous, would receive such a diagnosis that felt like a death sentence at the time. For her, this moment was a ‘turning point’. She finds it difficult to share her diagnosis with others. Two months later, the student visa ran out and she began the long and complicated procedure of applying for leave to remain in the UK on compassionate grounds because of her diagnosis. The claim was not registered and she had to make a fresh claim and her solicitor has called upon the fact that Susan’s case is a ‘legacy case’, one that has been in process for a long time. It is a claim that is still pending today. She has two sons in Zimbabwe.

Constance had been at the cooking session in the church. I had noticed her as a quiet and unassuming woman, leaning on the kitchen hatch and keeping a low profile when the conversation about gender roles had become heated. I had doubted that she would want to be part of the study but after the session had ended and we had eaten the curry, she approached me and said that she would like to be involved and we made an appointment to meet in her home the following day. She is in her late forties and was trained as a secretary in Zimbabwe and has worked in textile design. She arrived in the UK in 1993 with a six month visitor’s visa with the intention of studying. First, she applied for a work permit and was granted three years and later a five year student visa. She received her diagnosis in 2000 after routine antenatal testing in London. As a result of the initial referral letter from her GP being lost, the test took place when
she was already eight months pregnant. She began medication for PMCT immediately and was told that the chance of her baby being born without HIV was slim but that there was hope. She told me what she felt at the point of diagnosis, ‘I was really shocked you know, really depressed, I wasn’t expecting that, you know, I felt my life had come to an end’. Soon after this Constance applied for leave to remain on compassionate grounds, which she received for one year and that was later extended for another three years. In 2007 she decided with her solicitor to apply for indefinite leave to remain which was granted to her a year later. Constance has a sixteen year old son in Zimbabwe and a twenty-one year old in the UK. Her youngest son is living without HIV. She has very little contact with the father of her youngest son.

I met Grace for the first time at the sewing group. She arrived as the sewing machines were already buzzing into action and the heavy swathes of beautiful Holland wax prints were being laid out. The chat between the women was getting into full swing and we retreated to a quieter place. She is in her early fifties and was a self employed business woman buying and selling goods in Zimbabwe. She came to the UK in late 2006 as a visitor with a six month visa, coming to see her sister after a family bereavement. She collapsed in 2006 in her sister’s bathroom and was admitted to hospital. There she received her diagnosis and started medication. She told me that she had been ‘heartbroken’ at that moment and as she discovered more about the virus she began to piece together what had led up to this moment. Grace had been left a widow with seven children, after her husband was killed in 2001. He was in the army and travelled a lot and she thinks that he probably died with the virus. She told me that she was able to forgive her husband, she said ‘for what he brought into my life’. She has two sons in the UK and five other children in Zimbabwe. Whilst Grace was in hospital after her diagnosis, her visa ran out and she applied for leave to remain on compassionate grounds. This was refused and after a long
delay she was told in 2007 to return to Zimbabwe to look after her young children. She made a fresh claim in 2008, seeking asylum on compassionate grounds because of her need for access to medicine. Although not politically active, she was once attacked by members of the ruling party in Zimbabwe at the time and fears further attacks if she were to return. Her case is pending.

When I met Giftie for the first time at the sewing group, she appeared to be uncomfortable about discussing her story but at the same time she seemed to be willing herself to talk to me about her experiences. I perceived that part of her reticence was because some of the women in the group were unaware of her diagnosis. I had explained what I was doing and she was certain that she wanted to take part but there still seemed to be a struggle within her. She is in her mid thirties and arrived in the UK in 2000 with a six month visitor’s visa, seeking political asylum. Giftie received her HIV diagnosis in 2001 having felt ‘ill’ and going to her GP for a general check up. She began treatment immediately. She told me how she felt when she received the diagnosis, ‘when I was diagnosed, I was depressed and I was referred to a counsellor and then referred to a psychologist, because I was so depressed about it, you think of killing yourself,’. At the point of diagnosis, Giftie had no secure immigration status. She had over-stayed her visitor’s visa and her asylum claim had been refused. Having been diagnosed she applied for leave to remain claiming political asylum and compassionate grounds. The Home Office wanted her to produce more evidence of ‘networking’ and showing political activism in order to grant her political asylum. Giftie was granted indefinite leave to remain in 2007. She has an older daughter oversees and a toddler with her husband, with whom she is living in London.

The first time that I spoke to Ruth on the telephone she struck me as a very strong woman who knew her own mind and had no hesitation in expressing her
I realised that her resolve had probably been strengthened by all that she has been through. She told me, ‘we’ve cried, our tears have dried up, we are like whatever comes, I’ll face it because I’ve seen the worst’. She was a kind woman who looked out for others, as we sat down in the café it transpired that she knew the Ugandan woman who was serving us. She came over to our table and she and Ruth struck up a conversation about the fact that she hadn’t been for a massage in a long time. Ruth offers alternative therapies to women living with HIV and was clearly passionate about it saying that helping people to feel and look good ‘raised their self esteem’. She is in her mid to late forties and having undertaken secondary education in Zimbabwe, came to the UK in 1997 to further her education. She began working with an off shore contract after her studies in the UK. In 2002 she collapsed at work and was flown to England for medical attention and received a six month visitor’s visa. She was diagnosed with HIV and told me how she felt when she received her diagnosis, ‘to be honest I was happy because it’s a thing you will have lived with thinking I may, I may not, I may, I may not, I may, I may not, you are not too sure and at the same time being diagnosed in a place where help was it’s such a relief’. At this time she applied for leave to remain on the grounds of being able to have access to medicine in the UK. Due to circumstances out of her control the application was delayed, her existing visa ran out and she became an ‘over-stayer’. As a result her application was refused on the grounds that she had not complied with immigration rules. She was not allowed to initially appeal but later, after advice from her solicitor, began the process of re-appealing. She had not received a letter from the Home Office that she would be removed from the country. This claim has been pending since 2003 and includes an appeal on the grounds of the right to life and that she has formed networks in the UK. She has four children in Zimbabwe between the ages of eighteen and twenty-eight. Her husband died in Zimbabwe and she has subsequently remarried.
Joy is in her late twenties and full of energy and enthusiasm. She came to the UK to study in 2001. She was diagnosed in 2005 having been referred to the GUM clinic for a sexual health screening following a routine check up with her GP. She doesn’t remember the doctor discussing the HIV test with her before hand and it was something that she never considered as being relevant to her. Joy was shocked on receiving her diagnosis and had laughed at the time, as she relayed the story to me she pinched her skin and said, ‘I don’t look like someone who is sick!’ She told me how she was confused at the time and didn’t know whether she should cry or how she should respond to the news. It was a little later when she started medication that the diagnosis hit her, in combination with the side effects of the drugs she ‘went down’. She said, ‘I just went down, you know, yeah, it just hit me, mentally, emotionally, that’s when it hit me and say right, I’ve actually got HIV, of course they are saying that I’ll be OK but will I be OK?’. At one point Joy took an overdose and after that entered counselling. She is in a stable relationship now and has no children but considers having them in the future. When she was diagnosed Joy applied for indefinite leave to remain and has been waiting for a decision since 2005. The student visa has long expired.

Sandy came to the UK in 1999 on a six month visitor’s visa. This expired and she applied for a student visa which was refused and she was advised to return to Zimbabwe. She re-applied for the student visa and her passport was kept by the authorities and the case was pending until 2007. In the meantime Sandy received her HIV diagnosis having started the process of donating blood. She said that she had actually suspected that she might have HIV and told me how she felt when she received the diagnosis, ‘that’s when it really hit me and I thought [she took a sharp intake of breath], somebody knows, so it really, [she whispered] it wasn’t good, no bad news, bad news, I mean because how it was with the whole stigma thing, the way people portray you, it’s oh ‘you dirty, you
sleep around’ and I’m thinking to myself, ‘no I don’t, just one stupid mistake’

At that time she applied for leave to remain on the grounds of having formed networks and relationships in the UK. There were complications with her application, prolonging the process and she was refused leave to remain and advised that she could be deported. By that time she had not started medication and the authorities believed that she would not be in a more difficult situation by being removed and sent back to Zimbabwe. With support from her solicitor they appealed against the decision and she was granted leave to remain for five years in February 2009. She does not have any children. Sandy has just started ARVs.

Rose looked majestic when I met her for the first time, a swathe of material caught her hair up in a turban. She appeared to be agitated when we met and she immediately started talking about some financial difficulties that she was facing, a situation that had been complicated by her HIV diagnosis. This was having an impact on the support that she would be able to get from the council and her housing situation. Rose is forty and originally came to the UK seven years ago for a break. She had also been involved in some political activity in Zimbabwe and was granted indefinite leave to remain in the same year after a very swift process, although she could not remember the details of the case. She received her HIV diagnosis in 2006 after deteriorating health and weight loss. She was admitted to hospital for some time and they discussed the HIV test with her before taking blood. Rose told me that at the moment of diagnosis she had a sense of relief. She said, ‘And you know what, at the time I was just relieved that somebody believed me when I said there was something wrong with me because I had been telling somebody that there was something wrong with me’. I asked her if she remembered how she had felt at the time and she said, ‘I think it’s still sinking in, I, at different times, you deal with different bits of it’. She proceeded to explain how her current problem, a side effect of the medication,
was the neuropathy that had caused her to lose sensation in her feet and that she never went out without comfortable shoes on so as to avoid injuring herself. Rose has one teenage daughter in Zimbabwe and has very little contact with the father of her daughter.

Magdalene is in her mid forties and a new comer to the Women’s Action Group, having not taken part in many activities with them yet. She came to the UK in 2001 on a visitor’s visa of six months duration to visit family. Soon after her arrival she became ill and was taken to hospital where she was diagnosed with HIV. She told me that the diagnosis was both ‘good news and bad news’. She said, ‘I did not expect to be HIV but at that time I was saying, ‘ok it doesn’t matter whatever comes’ so it came out to be HIV positive so I said, ‘ok that’s fine’, ok it was a little bit touching, this is the end of the world for me, you know, like where life is concerned, love, relationships, which is the end of the world, which man could actually want a women who is living with HIV? You know? But on the other side it was good news that at least I’m going to live longer’. She was given the choice to start medication and stay in the UK or go back to Zimbabwe. She was granted a one year visa on compassionate grounds, which was extended for another three years. Before this visa ran out in 2007 Magdalene applied for indefinite leave to remain. This claim was acknowledged by the Home Office and she was allowed to keep living in the UK under the same conditions and viewed as an ‘asylum seeker’. She was informed that the process could take up to five years. She is waiting to hear whether she will be granted leave to remain. Her eldest daughter died with HIV in Zimbabwe a few years ago and her other two daughters, both in their mid twenties have left Zimbabwe to live and study abroad.

Patricia’s story illustrates the next step of the journey after diagnosis that introduced the women to the biosocial world. As initiation as a biological
citizen, she began to engage with the alternative biomedical explanations for her experience from the very moment of receiving her HIV diagnosis. At first she was ‘bombarded’ with a lot of biomedical information from hospital staff. A couple of months after her discharge from the hospital she was introduced to a support group and she began to acquire a new knowledge of her situation. She told me,

‘when I went there, I was surprised to see normal, normal people with HIV. I thought I would see skeletons there, I thought like that. Anyway I started attending meetings, when I started learning about HIV and TB and things like that, that is when I realised after having been taught, after having trainings about TB, that’s when I realised most of the symptoms they spoke of, I had them when I was in Zimbabwe, but just ‘cause I wasn’t educated about those things, so I never knew it was’

Rose and Novas describe this process of becoming a biological citizen as actively engaging with ‘biological explanations and forming novel relations with figures of scientific and medical authority’ (2005:446). Relations that traditionally exerted power on them are becoming much more dynamic. There is an opportunity then for an individual biological citizen to gain new knowledge and learn about their own fleshy body. They begin to operate within a new system, something that Rose and Novas call a ‘political economy of hope’14 (2005:442). In the experience of hope and despair I would often hear the women talk about others who did not have a biological understanding of HIV, as ignorant and in need of educating. Rose and Novas explain this as a ‘moral economy of hope’, where ‘ignorance, resignation and hopelessness’ about the future are disapproved of (2005:442). One of the women’s main priorities was to convey their new found knowledge to others. Biological citizenship does not remain an individual experience, people become ‘active biological citizens’ and get involved with spreading information, campaigning for rights, combating stigma,

14 Rose & Novas describe an economy of hope as one that considers biology to be ‘knowable, mutable, improvable, eminently manipulable’ (2005:442). They acknowledge the ambivalence though, that in the face of hope there is also anxiety particularly about the future of individual’s children, relationships and family as the women in this study described (Rose & Novas, 2005).
offering support and techniques for everyday management, alternative forms of therapy and demanding their say in the development of medication (Rose & Novas, 2005:448). In other words, the agents within the biosocial field call upon certain capital to bring about change. At the same time the process of becoming ‘body experts’ is underway (Shilling, 1993). It is within this activity that the group raises awareness about HIV and its transmission and has set up empowerment groups for women without children to find a new sense of identity as a childless woman. In the case of Patricia she became very involved with the HIV community, advocating for treatment, fighting stigma and extending her engagement to a political level. Currently, like a number of women in the women’s action group, she has been taking part in an initiative to measure HIV related stigma and discrimination in the UK\textsuperscript{15} as a facilitator. She started to get actively involved as a biological citizen a few years ago.

‘really I started getting really engaged, I really excelled those years as 2005 to 2007, wow, I was participating in almost every training that would come around and every course, I did TB course, TB training, I did interpretation training, I did HIV awareness training, loads of them’

Like all the women in this study, Patricia received her HIV diagnosis after arriving in the UK. She had had an acute illness having suspected that something was wrong. The UK does not impose entry testing for HIV, however the compulsory screening of immigrants for TB and HIV is being debated in the public health sphere, generating ethically infused discussions about controlling borders (Coker, 2004). In theory an individual’s HIV status does not have any bearing on their migration status by law but clearly interfaces with ethical and moral dilemmas characteristic of biological citizenship. Four of the women that I interviewed have already received an ‘indefinite leave to remain’. Three received it after a long time of waiting and often having been refused at least

\textsuperscript{15} The People Living With HIV Stigma Index: ‘a research and advocacy initiative to measure stigma and discrimination relating to HIV ( www.stigmaindex.org )
once. Since they have had to wait for so long, they become ‘legacy cases’ and can call upon the fact that they have formed relationships during that time as grounds to be allowed to remain in the UK. The women who have been given leave to remain have been granted entrance to participate in ‘national citizenship’. Never-the-less they have shared the uncertain journey that the other half of the group is still pursuing, participating in the ambivalent experiences at the point of diagnosis. For most, receiving a positive HIV diagnosis was a shock, ‘like receiving a death sentence’, marking ‘the end of love life’ and often accompanied by a period of depression. There was also confusion for some who had been faithful to husbands and partners for years. As Patricia put it most people in Zimbabwe, including themselves, treated HIV as a moral issue and associated it with death. For some there was a great sense of relief. These feelings were often followed by hope and the prospect of being in a place that could help them survive, where they could gain knowledge about their diagnosis and plan a future. However, this ‘economy of hope’ was tempered by recalling the friends and relatives for whom they had cared and who had died with HIV back in Zimbabwe. Giftie told me about how she felt when she received her diagnosis.

‘I was lucky to be diagnosed in this country, I’ve known people I’ve had relatives who have died of the illness back home, close relatives and I’ve cared for loved ones who died of the illness, but when you are diagnosed here you are kind of lucky because you have got all the support they broaden your knowledge about the illness and you have got counselling and you can make a choice and you still have a voice,’

The Biosocial Field & Access to Biomedicine
Nguyen discusses the idea of therapeutic citizenship in the context of a ‘friendship centre’ for people living with HIV in Burkina Faso (2005). He introduces ‘therapeutic citizenship’, in the context of accessing medicine, as one that makes claims ‘on a global social order on the basis of a therapeutic predicament’ (Nguyen, 2005:126). In other words, he explains how individuals...
procure therapeutic resources in the context of biomedical knowledge, something that is expanding its reach trans-nationally. Nguyen argues that this therapeutic citizenship is a bio-political one, ‘a system of claims and ethical projects that arise out of a conjugation of techniques used to govern populations and manage individual bodies’ (2005: 126). Nguyen describes the way that individuals with HIV in Burkina Faso make use of their social capital to acquire drugs (2005). Drawing on their social, economic or cultural capital has not been the primary mechanism through which the women in my study have been able to access medical treatment. Nguyen acknowledges that in ‘many Northern countries, national health insurance has meant that citizenship automatically confers access to treatment’ (2005:142). Not all the women had ‘national citizenship’ on accessing medicine but as I have described the women who were documented migrants, refugees and asylum seekers were entitled to free medical treatment in the NHS and limited social welfare benefits (Ndirangu & Evans, 2009). Those who had overstayed their visas were still able to access medicine. The convoluted immigration journeys makes it difficult to completely distil what happened at the time of beginning treatment and how the immigration authorities perceive the women. They told me that ‘over-stayers’ seem to be considered as ‘asylum seekers’ at some points, meaning that they could technically continue accessing medication. Apart from this confusion the Joint Committee of Human Rights 2006/2007 recommended that on the basis of human rights the UK government should provide free HIV/AIDS treatment for refused asylum seekers and thereby uphold their commitment to universal access to HIV medication. In practice a person will be able to access health care regardless of their immigration status when they need care largely because of the way that the NHS operates. In theory, an undocumented migrant will be asked questions but I only heard about this on one occasion. Although Nguyen’s discussion involves another context, what is interesting is how he recognises the ‘complex bio-political assemblage’ that those seeking treatment are part of and
the ‘moral economies’ that are employed when negotiating therapy (Nguyen, 2005). For these women engaging as active biological citizens and at the same time being in a precarious immigration situation, discussions and claims about their health include attention to rights\textsuperscript{16}.

**Immigration & Leave to Remain**

Each woman in this study entered the UK ‘legally’ in the eyes of the law. The HIV diagnosis has produced urgency for them in finding clarity about their immigration status since the possibility of receiving adequate medical care in Zimbabwe is limited. However, a positive HIV diagnosis does not have unequivocal bearing on an asylum claim and compassionate grounds do not necessarily carry legal weight. There may never-the-less be some possibilities for negotiating a claim on health grounds. Four women have already received indefinite leave to remain, claims that were granted for reasons other than compassionate grounds. One woman must renew her leave to remain in four and a half years time and six have claims that have been pending for up to six years. Procuring leave to remain and being able to continue their medication is what is at stake for these women. Sandy said to me,

‘The choices was either to stay here and fight to stay here [pause] or go back and die’.

Sandy’s immigration journey has been a complicated one, like the experience of most of the women. When she was diagnosed with HIV her immigration status was unclear but she needed to secure the possibility of staying in the UK. The terminology used by the Home Office is confusing for the women and perhaps overlap at times but Sandy was labelled an ‘over-stayer’, others may have considered themselves ‘asylum seekers’ in a similar situation. At this point the possibility of staying becomes a human rights issue in the eyes of the law.

\textsuperscript{16} Landzelius has described such debates in terms of a ‘politics of vitality’ (2006).
Human rights forms the basis of the mechanism through which a person can apply to stay in the UK regardless of their HIV status. It is a discourse of rights that the organisation and the women have embraced, something that they are well versed in. The immigration Act of 1971 forms the basis of immigration law in the UK. Sandy applied for ‘discretionary leave to remain’ something that someone who has overstayed their visa has the right to do. The Home Office only grants discretionary leave in exceptional and extreme circumstances (Soomre, 2008). In these cases individuals may refer to Article 3 of the European Convention on Human Rights which prohibits torture. The convention states that ‘no one shall be subjected to torture or to inhuman or degrading treatment or punishment’ (Soomre, 2008). However, the same law says that whilst the Home Office can exercise discretion in deciding not to deport an individual, if they do decide to send somebody home this is not in breach of human rights legislation (Soomre, 2008). This is something that was illustrated by the case of ‘N’ v Secretary of State for the Home department in 2005, one amongst other such cases that the women are very familiar with. A Ugandan citizen with HIV claiming asylum was denied it. The court upheld that Article 3 would not be violated solely on the basis that the medical facilities in the country of origin did not match those of the country in which the individual was claiming asylum (Soomre, 2008:10). It was said that the individual ‘would be in no worse position than the majority of people in his country of origin who suffer from the same condition, then a grant of Discretionary Leave would not normally be appropriate as it would not be an exceptional case’ (Soomre, 2008:10). This has been contested not least because of the way that it seems to contradict the UK’s policy aim of universal access to HIV therapy. I was travelling on a train to meet another woman when I read this report and the words of Ruth, who I had met the day before were ringing in my ears. She is waiting for a decision to be made by the Home Office, a source of great uncertainty. Her case is pending and she
whether she is perceived as an ‘asylum seeker’ or an ‘over-stayer’ is unclear to her.

‘I’m waiting for a decision to be made by the Home Office whether I should stay here or whether I should go back home and at the moment I don’t see them saying go, because it’s not a place where it is conducive for people living with HIV, they will just keep me and not letting me get on with my life, it’s like all these years you have never lived...yes, we have applied on human rights article three, non, of which they have derogated (laughs incredulously) it’s amazing, and I’ve also applied on article eight, right to family life because I’ve got family here, I’ve also applied on article two, right to live because if you send me back home I’ll die because there is no medicine, they haven’t replied, they are so disrespectful’

The same report by Soomre challenges the way in which the Home Office generates and collects data about the situation of countries of origin (Soomre, 2008). Salient to our discussion is the way in which the Country and Information Policy Unit (CIPU) produces Country of Origin Information reports (COIs) about the provision of HIV medication in Zimbabwe, information that is used by those involved in asylum claims (Soomre, 2008). It has been claimed that medication in Zimbabwe was ‘readily available’ and that members of parliament were ‘advocating to make ARVs for those in need countrywide’ (Soomre, 2008:18). Whilst COI reporting has improved in Zimbabwe and seems to give a clearer picture of reality, particularly in light of current political events, this sort of information has been used in cases that result in rejecting peoples’ claim to asylum on medical grounds (Soomre, 2008). I heard one story of a woman who had been part of the woman’s action group and had been deported. Others in the group rallied round trying to get together enough medication to send to her. The women in the study were still living with very real uncertainty, tangible realities that their claims may be rejected which often becomes exhausting.

Ruth’s story illustrates how individuals negotiate the application procedure with their legal advisors, finding the most beneficial angle to approach the claim.
Article 8 of the European Convention on Human Rights offers another tool to leverage an immigration application. It concentrates on private and family life, establishing relationships and involvement in the community. If individuals can prove that they have established these networks there appears to be good grounds for a case to remain. In the case of the women in this study they often fall under ‘legacy cases’ where article 8 becomes relevant. They wait for years to hear if they can stay in the UK, in the meantime forming relationships and participating in social networks often within the HIV community. Patricia managed to impress the Home Office with her enormous file of information about her involvement in support groups and the public speaking that she had done. This could be described as a form of capital. Whilst she gained knowledge of her own situation as a biological citizen through engagement with the biosocial field, she was able to form networks, gaining social capital and ultimately ‘indefinite leave to remain’ and national citizenship. Individuals can negotiate the social field, gaining resources, which with guidance from legal support can result in entrance to national citizenship. For those waiting to hear if they can stay and negotiating the process there is immense concern and for those who have been granted leave to remain they know the journey of waiting and the energy required to enter the legal process. The women are unable to work during this period of waiting or study as in the situation of Joy.

*The Decision to Remain & Implications for Motherhood*

The diagnosis itself creates many challenges to the role of motherhood that will be explored in the following chapters. Here I am interested in the immediate implications for the women of deciding to stay in the UK. Some have been separated from their children as a result of deciding to stay, some have been able to be re united with children in UK, some have given birth to their children whilst here and some are without children but the decision to stay means that they may have the opportunity to have healthy children in the future. Patricia’s
experience at the time of her diagnosis was shared by all the women who had children, as a painful separation. She has subsequently been able to be reunited with her children. However, for those who have children in Zimbabwe or neighbouring countries and are still in an ambiguous immigration status, there is a very real uncertainty as to whether they will be able to see their children in the future.

Six of us sat in an upstairs room of a small house on the banks of the River Thames, it’s a meeting place for anybody in London living with HIV. The atmosphere was buzzing; gay men and African women exchanged embraces and gossip. I felt like somewhat of an outsider and was acutely aware that my insight into the reality of the daily experiences of these women would be limited. My feelings were pricked again later when they spoke about the restricted level of understanding of people from outside the HIV community. I became very self conscious sitting in the small dining room. Sometimes they slipped into Ndebele or Shona and the feeling of outsider became even more acute. We had eaten a large and delicious lunch satisfying the appetite of some who had hoped that there would be more substantial food than sandwiches available. ‘We are Africans, we don’t eat sandwiches!’ one woman had said to me when we were planning the discussion. The kitchen seemed to be the hub of this meeting place and one woman said to me that she used to go there just to eat when she was too sick to cook for herself. The kitchen would prepare food for those who did not have enough strength to cook and friends could deliver it to them. We continued our conversations upstairs together. The group discussion turned to issues relating to immigration and choices about leaving children behind in Zimbabwe.

Rose began ‘it’s never an easy choice-

‘I don’t think it’s an easy choice’ said Sandy thoughtfully.
‘It’s never an easy choice, everyday you beat yourself up about it and think, why did I do it? Could, should I have just stayed there and so on, it is, everyday you beat yourself up about it.’ Said Rose as she turned to Patricia and continued,

‘Even if like Patricia, you left them home for a little while and then you got them, for that time that you didn’t have them you still think of that gap in between your coming here and their coming here as maybe there was some other kind of support I could have given them during that time, maybe something happened to them while I was away, maybe the little one fell and I couldn’t kiss it better. You worry about all those things.’

Patricia responded, ‘you worry about everything as long as you are not close to your child’

Rose, raised her voice and became more passionate, ‘even when-’

Patricia, interrupted saying in a steady tone, ‘so what is family? I think families should be just close to each other, that’s it’

Everyone agreed, and the conversation became ordered again and Patricia continued,

‘I think immigration on the contrary I mean determines er I mean the way mothers act or feel about family, it’s got this wall, that being a mother or you are not a mother, I don’t care, I as immigration you are not going nowhere, it determines where you stand-’

‘Who you are-‘ added Sandy.

‘where you go, what you think, even you think but with that barrier you won’t go nowhere’. Patricia said.

The ambivalent experience of the opportunity to be kept alive and the sense of being immobilised by a wall around them became clear and something shared by the women. Rose said that she was so stressed and her health is affected by the thoughts about whether she will be able to see her daughter again in the future. Ruth described her experience as a mother, ‘it’s like looking after your children with a remote control’. Some wondered if that meant that they were actually fulfilling the role, some thought they could still fulfil it without a problem.

**Chapter Conclusion**

At the point of diagnosis, there was a choice to be made. These women could take hold of the opportunity to be kept alive or go home with their reputation in
tact but to effectively die. This moment of diagnosis is a crucial one for each woman not only in coming to terms with HIV and all that it meant to them. The moment is also inextricably bound up with the immigration struggle that continues to shape their lives today. Separation makes it very difficult for the women to fulfil their role as a mother. By staying in the UK the women enter the biosocial field and begin to negotiate a new kind of power that comes with the new knowledge while they are restricted by the boundaries imposed on them by the state. They begin to embody new meanings about themselves and their sense of identity. As active biological citizens they draw on capital and begin to challenge the things that might restrict their ability to receive medication. We can begin to see a reorganisation of power relations as they enter the biosocial field and pick up a discourse of empowerment.
Chapter 3: Disclosure: How to tell people that I have HIV

‘there is a strong belief that the early years of breast feeding or the early months of
breast feeding help the baby protect them from illnesses and its difficult to tell your
mother-in-law, she’s elderly, she grew up in Zimbabwe she’s come here as an elderly,
now she resides here, she’ll ask ‘why are you not breast feeding the baby? Because the
baby needs the milk form the mum and we can’t afford milk,’ this, this because we were
then not working’

(Giftie)

Giftie had seemed initially to be slightly reluctant to share her experiences at
first, after the interview had finished she told me that she was surprised that she
hadn’t cried, she said that she normally does when she talks about her story.
Later, I realised that her journey as an ‘active biological citizen’ was just
beginning. She said during a discussion a few weeks later with some other
women that she never speaks to ‘outsiders’ about her HIV status, something that
the other women agreed with and deeply understood. She said that it is only
recently that she has ‘sort of grown’ and is able to share her experiences with
another friend who has the same diagnosis. I found it intriguing that she
associated being able to talk about her HIV status with growing. However, it
was fitting for a developing active biological citizen. Giftie has been diagnosed
with HIV for about eight years. Her initial asylum claim was rejected and in the
meantime she became pregnant. Her story illustrates the possibilities that being
a biological citizen in the UK offers to women who want to become mothers. It
also highlights some of the most tricky issues relating to disclosure when taking
into account the context of social relations and community within which a person
lives.

Disclosure

From the outset of this chapter it is necessary to consider what I mean by the
concept of disclosure and that it refers to telling sexual partners, families and the
wider community about your HIV status. It is often something that needs to be
contemplated soon after the diagnosis. Each of these social realms applies to the
experiences of the women and the role of motherhood. It is a subject that is extensively discussed within the biosocial field. It is often talked about within support groups and in fact appeared to be a feature of the women’s initiation as biological citizens. Being taught how and when to disclose ‘appropriately’ was an important aspect of becoming a biological citizen. One of the women told me,

‘From this support group that we go to we are really, we have been well educated on where to disclose’

Rose also discussed how disclosure was a feature of taking part in support groups,

‘there is never a conversation as interesting as the day you go to the support meetings and you discuss disclosure and sex, it just goes on and on, and every time you discuss it you discover something new that may happen to you that may not have happened to you but that you need to be prepared for’.

A human rights discourse has driven the debate about disclosure, originating in the gay rights movement of the 1950s and being translated into the HIV/AIDS discourses of the present. The language of ‘coming out’ heard in the gay rights movement is echoed in the language of the biosocial field, where active biological citizens advocate disclosing ones HIV status. Rose and Novas recognise that the ‘obligations’ and forms of biosociality are specific to certain contexts (2005). The active biological citizen of Europe has a concept of citizenship and personhood that links to the ‘history of previous forms of activism in the feminist, gay and AIDS movement’ (Rose & Novas, 2005:451). Biosociality for the women in the context of this study was birthed in London, UK and is very different from that in sub-Saharan Africa. One can imagine the process that the women have gone through in order to understand what disclosure means in the context of the UK having been used to a very different way of being in Zimbabwe. These women were largely used to the situation in Zimbabwe where you do not tell if you have HIV. As Patricia described in
Chapter two, a woman with HIV should ‘die gracefully’ in order to maintain her good reputation as a wife and mother. It is the ‘activists’, those ‘active biological citizens’ who have usually arrived at a place where they will advocate for the benefits of disclosure, never-the-less they themselves have been on a journey to get there. The women that I met who used this language themselves and associated disclosure with support and moving forward understood those who found it difficult because they had been there themselves. There was still ambiguity in their own lives and they would be careful whom they would tell. By not disclosing their HIV status they would ensure their own social survival. The woman who had been part of beginning the women’s action group had reflected on the women who had contributed so much at the ‘risk of rejection and ridicule’.

On one level ‘coming out’ means that as biological citizens the women can move towards finding support within the biosocial field. Furthermore, they can take hold of their rights as women and campaign for the rights of other women and fight to decrease such things as their experiences of stigma that they had described. Disclosure is also about the prevention, testing and treatment of HIV, a ‘tool’ in the hands of the public health field. Disclosure and prevention are intimately linked in this debate. There has been a strong presence of rights and responsibilities in the history of debates about HIV prevention. Throughout the 1980s and 1990s HIV prevention was closely associated with guarding human rights, not forcing disclosure and relied upon voluntary testing (Scheper-Hughes, 1994). Since the mid 1990s there has been a shift towards a sense of social responsibility when it comes to prevention and testing. In an early essay, Scheper-Hughes explored how AIDS had shaped political and moral thinking (1994). She said that she found an ‘uncanny consensus in the social science and international medical communities with respect to thinking about and searching for appropriate responses to the global AIDS catastrophe’ (Scheper-Hughes,
It was agreed that AIDS would be treated as a special case. In other words AIDS exceptionalism was birthed, where disclosure becomes an individual choice. It is a debate that is still being played out in the biosocial field and one that is clearly heard in the stories of the women with whom I spoke. They sometimes agonised over whether to disclose or not and match the reality of their lives and relationships with the discourse about their rights and responsibilities. In the case of the UK, routine antenatal HIV testing is voluntary but as one woman put it, which pregnant mother with the prospect of medical treatment would not choose to take it? The woman in this study who was tested when she was pregnant had a very supportive experience, however, it is clear from what I heard from the other women that there is a varying amount of support surrounding testing. Concerns have been raised about how much genuine support is available for women at routine antenatal testing (Welbourn, 2008). Support is paramount for the women to survive, especially where existing support structures may be lost in the process of migration. Scheper-Hughes has questioned treating AIDS as an exceptional case, with the example of Cuba, where routine testing of returning troops occurred. It became an ethical debate for her, the sort of ethical dilemmas that we see characterising the biosocial field and the lives of those who inhabit it. Should individual rights be held above social responsibility? This debate, observed within the global community, resonates with the ambiguous ideas within the biosocial field that I encountered about disclosure but never-the-less advocated by those very active members. Whilst some were adamant about disclosing, it was clear that the experiences of these women in the group tended towards ‘individual rights’. They advocate for educating women about their rights and about how, when and where to disclose and that there was no need to disclose to everyone. Of course the pragmatics of life makes it impossible to prescribe particular ways of disclosing as the stories of these women reveal. Rose and I were discussing the subject and she explained how it was something that had to be negotiated.
‘Oh yeah, it’s like knowing who to tell and who not to tell, it’s very tricky, it’s very, very tricky and there’s no like formula for it and you take it as it comes, sometimes it works in your favour, sometimes it works against you. It’s always there, it’s like a minefield and at any point wherever you are going you have to be really careful in case something blows up in your face.’

There were many things at stake for these women in disclosing their status. There is still a very present Zimbabwean community in the UK that has not been inducted into the biosocial world, for them HIV is still a very moral issue. Even within the Women’s Action Group, which includes women who are not HIV positive, it becomes a delicate issue when coming to discuss certain things when they are all together. Like Giftie and her desire to keep her reputation intact, what is at stake is maintaining moral integrity and social survival. Giftie had told me how the stigma in Zimbabwe makes an HIV diagnosis worse. I asked her what she meant by the term stigma and she told me,

‘What happens is, if you are said to be HIV you are rubbished or people think that they can’t share a cup or a drink or anything, people can’t shake your hand, because they haven’t got that broader knowledge about it, they think, I’m dead that’s the end of it,’

She continued,

‘Back home you can’t do that [disclose], you can’t even share it with your close ones or your parents because then they will think you got this illness, you’ve been doing prostitution or you’ve been doing the wrong things, where as you can get it through different ways through blood transfusions, through changing needles, you know? Whereas back home, it’s only through sexual intercourse, unprotected sex, that’s all we knew when we grew up.’

Giftie spoke about the things that HIV is associated with in Zimbabwe, death and sexual immorality, something she had grown up with but had changed for her. This was something that I heard about from most of the women and they told me it is normally referred to as AIDS, not as HIV. A sign perhaps of the lack of structural factors that can treat HIV before it develops into AIDS. This ‘social body’, for which HIV is a moral issue, is still very present in Giftie’s own life in the UK. Despite her own growing knowledge of her situation and
alternative explanations that she learned, these meanings that have been embodied and persist in the context of the Zimbabwean community in the UK lead her to choose to avoid certain situations in order not to be forced into disclosing her status. This for her is what prevents her from being more open about her HIV status. She said to me ‘it’s a few people who can come out and say ‘oh, I’m HIV positive so what?!’’. Her mother-in-law represents something of that social body. I detected in the way that Gifty spoke about her that there was something of the historical dynamic between mother-in-law and daughter-in-law that I had heard about, often accompanied by blame. She told me what happened when her baby was born,

‘for one month he gets the liquid, you have to just give him so you can’t visit people because you have to be secretive, you have to give him that, people will wonder why and that, you have, did I keep it in the fridge? Oh no, I had medication that I had to keep in the fridge so I can’t visit people as well, because I had, my medication had to be in the fridge [laughs].’

I asked Gifty what it was like when people came to visit her and she replied,

‘When they came to my house it was difficult, you’d be very, very uncomfortable in your own house,’

It was difficult if visitors started looking in the fridge where Gifty kept her babies medication and she recalled the decision that she and her husband made about his family staying over,

‘because it’s a tradition back home that the mother comes and stays with you for a couple (of weeks) so we had to agree between us that she can’t stay with us, it’s difficult because medication has to be given at certain times,’

She explained how she felt when the visitors would start enquiring about why she was taking tablets and she said,

‘Well it made me feel uncomfortable, to an extent that I didn’t want anyone coming to my house, that first year, I wanted to live on my own and that’s when people are so excited and eager to see the baby and to help out’

_Telling Sexual Partners & Becoming a Mother_
Most of the women in this study were already mothers and disclosure to their children presents a significant challenge that will be discussed in the following chapter. However, for women who would like to fulfil the role of motherhood, despite support from the biosocial field, the first step for them is finding a loving relationship. Marriage was perceived as an important part of the role of a woman and discussed by the women as something that usually comes before becoming a mother. The decision to try to become pregnant is a big one and apart from wanting to offer security to a child that an uncertain immigration status doesn’t allow for, the women must first disclose their status to their partner. Other women in the study who have engaged in sexual relationships have echoed similar stories of the hurdles of telling sexual partners with some deciding not to disclose. It was a very difficult thing for Giftie to tell her partner that she had HIV, she said to me that she had been scared to tell him.

‘You are so scared that they will just reject you, reject you, you know once they know your situation.’

In fact her partner found out from another source after they had been having unprotected sex, a discovery for her that was very scary and shaded with guilt on her part.

‘I just thank God it didn’t get me into big trouble because you can get arrested for that, I know a few people who have got arrested for that. So thank God he didn’t get me arrested, that’s nice, you know I respect him for that’

The criminalisation of HIV transmission has been flagged up as a human rights issue. In England and Wales, the Offences Against the Persons Act (1861) has been used by the courts to include the transmission of a serious disease (IPPF, 2008). HIV has been the only disease so far resulting in a successful conviction under this law. Such a move towards criminalisation could have serious implications for women’s choices about entering sexual relationships. With
criminalisation come further potential barriers for women wanting to become mothers who may take on the increasing blame that labels them as potential vectors to transmit HIV to the unborn foetus. For the women in this study who have already journeyed against perceptions in their own community this would represent a very real set back. As we shall discuss in Chapter five, further development of such action presents further barriers to the sexual and reproductive rights of women and their choices about pursuing motherhood. Whether this law will become consistently used against people living with HIV, remains to be seen. Never-the-less there is an existing fear amongst individuals which influences their choices about disclosure and perhaps about getting into relationships and becoming mothers. During a later group discussion Patricia said that many women living with HIV were deciding against entering into sexual relationships for this very reason, something that the others agreed with,

‘talking things like your relationship, of course, the majority to be honest with you, the majority of women living with HIV no matter what age they are they are not having any sexual activity . . because of the fear, the fear of being er, criminalised, the fear of maybe infecting other people, you know now those who are engaging to be honest with you, those are the most active ones who have been in this area for a long time’

Joy is in her late twenties and considers becoming a mother one day. It’s a priority that she had to relegate when she received her diagnosis. She thinks that she will get married one day. Despite being in a loving relationship and having the support of her boyfriend and the medical field, she wonders if she could provide the security and basic needs for a child at the moment. Providing these things is crucial for her but something she thinks is questionable at the moment because of her immigration status. She is still waiting to hear if she can stay in the UK. Joy is an ‘active biological citizen’, when we met she was on her way to facilitate a group for people who had just received a positive diagnosis. She was full of energy and her mobile phone rang several times during our
conversation and she advised her co-worker on plans for the evening session. She talked about her experiences of meeting potential boyfriends.

‘That’s always been my thing say ok, I’ll disclose at the beginning of the relationship ’cause some people did condemn me for that, ’why did you have to do that? ’What if you meet a hundred guys having to say?’ I was like, ‘then a hundred people know’’.

Despite always disclosing her HIV status at the beginning of a relationship Joy told me that it was not always easy. She recalled the time when she started disclosing to the men she would meet and that when someone didn’t ring her back she felt very bad and rejected. Susan spoke about a similar sense of rejection. She had found it very difficult to disclose her HIV diagnosis to anybody in the beginning but felt that she was at ‘bursting point’ and needed to share her situation with someone. She decided to tell a good friend from Sierra Leone living in the UK who ‘did her crying and her mourning and then just said goodbye and never came back’. Around the same time she received another blow when she decided to disclose her HIV status to a man she had been seeing.

‘At the same time I had fallen in love with another man and erm, when I got the diagnosis I went to his house and told him, this is the diagnosis, and luckily I had not had sex with him yet so, he said fine ok, so he showed me the door, I said ok, so if this is how it is going to be received by people why bother telling them, just withdraw into my shell and keep quiet. Deal with, my life.’

Referring to those situations she said, ‘for me that was a lesson, so I will not tell anyone’. Susan already has her own children and on another occasion she told me that she doesn’t see herself getting into another relationship. Partly because she doesn’t see the point, she’s ‘seen it all’ and ‘done it all’. She added ‘I’ve closed the door’ and I perceived that she may just have been too let down in her relationships and couldn’t face further rejection.
**Acceptance within the Wider Community**

Disclosure is played out within the context of the wider community. For most women there was a clear distinction between disclosing within the ‘safe’ context of the biosocial field that offered genuine understanding and support and one outside of the field where one would run the risk of being recognised. I heard stories of other women living with HIV for whom disclosing in the safe space of the support group was too much and they would keep their experiences between themselves and the medical field. The potential for the active biological citizens to affect change through education was also important in finding ways to disclose to the wider community. It was often the eyes within the Zimbabwean community in London and the UK that the women wanted to avoid. The women often referred to the wider community as ‘ignorant’ and without sufficient knowledge and as a result it was impossible to experience acceptance as a woman and mother living with HIV. The present concern for the women in such a context, where education has not yet taken place, is rather to be able to survive socially. Despite the fact that Patricia is very comfortable about talking about her story she chooses to avoid talking about it in the area where her children go to school for fear of gossip (and stigma). Constance also protects her children in this way because she doesn’t want them to be treated any differently from other children. I argue that it is the persistent perception about HIV/AIDS that remains embodied within the experience of the women, which influences the choices that they make about disclosing. Where they haven’t been able to educate or are unsure of people’s understanding they will be very careful. This sense of caution seemed to be strongest within the context of the Zimbabwean community. Joy is very well connected within the biosocial field and she has observed some of these dynamics within the Zimbabwean community and the deeply entrenched ideas about the body with HIV even in the presence of ‘new’ knowledge.
‘I don’t know many Zimbabweans who are out there openly living with HIV, I do know that they are out there but they don’t talk about it. I think it’s because of the stigma that’s been instilled, you know that doctrine that you, you know that’s difficult to try and break away from, if you don’t have that initiative to say, that’s my life I have to lead it the way I want to’

I was curious to know what Joy meant by stigma and how it reflected the explanations of the other women. Still referring to the Zimbabwean community in the UK she said,

‘You know the, the, the people still think that having HIV you are going to die erm and that’s the school of thought, there’s still even if they know that you are not going to die, even if they are living with HIV and they know that they are not going to die but, I think it’s the telling of other people and the people are like OK, and the fact that OK the gossip as well and the fact that you know how people are so inquisitive, they say OK so if you are HIV positive it means you’ve slept with, OK this is your boyfriend, and so you’ve slept with that boyfriend and that boyfriend, they will start counting ways of how you have gotten it, and how do you know I got it through sex?’

A Christian faith was central to the lives of the older women in this study and has been a source of strength and refuge. Unfortunately, the Zimbabwean church has represented a place that does not share the journey with the women. Speaking like a true ‘active biological citizen’, Patricia said that there was ‘real ignorance’ in the Zimbabwean churches about HIV. It appears to be a place that perceives women living with HIV as deviant. For some this has meant being marginalised within the church and led to them leaving and attending different churches. Those who have had difficult experiences are now more cautious about disclosing to people in Church.

**Passing**

I perceived that in many social contexts outside the biosocial field of women living with HIV, where there is little biological knowledge about HIV and its transmission, women have experienced finding acceptance difficult. There are of course exceptions to be found which were within trusting relationships. However, within the spaces where women and mothers living with HIV were
not accepted it became paramount that they must survive socially. In this case ‘passing’ becomes crucial and being able to fulfil the role of woman and mother ever more pressing. Most of the women went through a time when their material bodies betrayed their health status and the possibility of passing was impossible. Patricia recalled one occasion on a bus when some other women were talking unkindly about her in Zulu, unaware that she understood everything. One of the women said, ‘that one looks ill’. Her daughter was with her and asked why she hadn’t confronted them. This situation had got her down at the time but she said to me that she hadn’t said anything to the women because ‘in those days I wasn’t very empowered’. As she told me the story it felt like she was referring to a completely different era in her life and a woman that I couldn’t match with the vibrant, confident one who sat before me. There was a great sense that her understanding of her identity now and who she was had shifted. Now that the women’s material bodies look very healthy, being able to present them as normal as possible is important in many situations outside the understanding relationships in the biosocial field and for some a mechanism to retain their reputation as a woman and mother. Rose told me,

‘when something is wrong with you inside it’s very important that you fit in that you look as normal as possible so you make an extra effort to look like everyone else, so that people are not staring at you because I did like go through that whole year when I was looking like a scarecrow and everybody would just stare at you on the bus and nobody would want to sit next to you on the bus, cause you were creepy, because you were like a walking grave, that definitely happened, but now that you know I’ve gotten to a point where I look more or less the same as everybody else,‘

Chapter Conclusion

The dilemma of disclosure for these women echoes the global debate. It is for them linked to their pursuit of knowledge and wanting to educate others. Disclosure remains a very difficult thing with implications for them in fulfilling the role of woman and mother. Outside the biosocial field of HIV positive women and particularly in the wider Zimbabwean community in the UK, HIV
persists as a moral issue and makes it difficult for them, despite their own knowledge to break free from the embodied experience as a woman living with HIV. This shows itself in the way that they avoid disclosure and negotiate certain social fields. As such, presenting their material body as ‘normal’ and not being forced to disclose their status becomes an important mechanism for social survival. Being able to fulfil the role of mother is part of this mechanism as spoken about by Giftie and especially under the gaze of her mother-in-law. The overwhelming feeling amongst the women is that education and providing people with the knowledge that they have acquired is paramount to being able to move forward, a view fitting to the active citizen.
Chapter 4: Managing Bodies: Being an HIV Positive Mother

‘if I can get really sick you know, that I cannot be able to do things for myself and that I can rely on my children, I really think of those times whereby the time when I’m not able to do anything for myself, whereby my children have to rely on other people, rely on other organisations to help them, yeah those are the challenges that I have you know, I feel pain when I think of those things you know . . . I think of will I ever reach those stages in life whereby I won’t be able to do things for myself, you know, what’s going to happen to my children who’s going to take care of my children, you know I think of that a lot’

(Constance)

Regardless of whether the women who already have children come to terms with their HIV diagnosis themselves and the hope that their own bodies can be managed successfully, their individual bodies and identity are inextricably bound up with their role as mother. As a result the management of their own bodies involved their relationship with their children. Constance told me that if her body was healthy, she could fulfil her role, if it was not then she feared for the future of her children. Her greatest challenge was being able to manage her own body in such a way that enabled her to continue managing her role as mother and her relationships with her children. This was something I detected in the stories of the other seven mothers in the study. Furthermore, for some, the ability to manage their HIV and stay healthy was something that made them reluctant about considering having more children in the future.

Individual Bodies

The individual body is experienced within the context of the social body. Never-the-less, it is clearly experienced as a fleshy one that fails and is constantly reminded of its frailty.

‘every night when you are taking medication it reminds you that this is it, this is life, this is the rest of your life and erm, last year, quite a few people dropped dead, strange cancers and things and these are people who have been living with it for such a long time and they looked healthy and you thought you know, they are fine . . . they were friends within that whole circle you know . . . the people you saw like in your day to day life of doing HIV and they were people you would have referred to and then all of a
sudden there they were gone you know and then it reminds you that you are pumping your body full of stuff that you don’t know what it’s doing to your body and you don’t know how long your body can take all this stuff and you don’t know the affect of it, you don’t know the long term affects’ (Rose)

The individual body is present as a material reality that embodies to a greater or lesser extent the expectations and values that have been conferred on the women’s body. It might be the habitus or ‘world view’ of the experiences of gender inequality from the past or the social expectation to bear children and be a good mother. However, the way that the women understand and relate to their own body has shifted with the acquisition of new knowledge. The immediate reality of experiencing and needing to manage their own bodies affects the way women relate to their individual body.

**The Forming & Managing of the Biomedical Self**

The women had discussed their ambiguous immigration status and attitudes of the community outside the HIV networks as things that constrained their independence. During this process the women were simultaneously engaging in a journey that was transforming how they saw themselves and eventually ‘empowering’ them. This journey has shaped the way that they manage their own bodies and relate to others. Whilst biological citizens are taking on board new specialised scientific and medical knowledge and becoming active, what Rose and Novas call ‘informational bio-citizenship’, they take a dynamic role in increasing their own ‘biomedical literacy’ (Rose & Novas, 2005). In other words, ‘the language with which citizens are coming to understand and describe themselves is increasingly biological’ (Rose & Novas, 2005:446). This knowledge acts as cultural capital that can also be used when negotiating with the medical field. I had set out to find out if and how women ‘embodied’ the meanings associated with HIV and consider their own sense of self. It was clear that these women were understanding and describing themselves as biological citizens, rather than as objects of social discourses that labelled them as ‘dirty and
diseased’. The social context of the biosocial field was important in generating this new sense of the ‘biomedical self’. This new way of seeing themselves has initially come from biomedicine and filtered into the activities and language of the support groups.

Individuals take an active role in developing their biomedical literacy. The women had initially first heard about CD4 counts and viral loads at the point of diagnosis, they had learnt about these phenomenon and were now describing themselves in those terms. The language of the CD4 count and viral load was in use by the women as a way of describing themselves and as a sort of thermometer for how they felt. This concept of reconfiguring personhood has been discussed by Martin relating to the development of new ways of looking at the body and society (1994). She argues that in an age of HIV and AIDS people have used the immune system to organise and comprehend their lives and in so doing conceive of a very new way of looking at self (Martin, 1994). Many of the women remembered their exact CD4 count at the time of diagnosis and used it to describe to me how they were at that time. When Rose had talked about her stress levels she identified her CD4 count as being closely related to how she felt.

‘And then like recently because I’ve been stressed and everything has been like up and down my CD4 has dropped to where it’s below 200’

Magdalene described to me how she felt about herself.

‘Yeah and erm, ok, er after that time my CD4 count was very low at 160 and my erm, what do you call, CD4 count, my system, I would say there was a lot of HIV in my blood so three weeks after that it was, the amount of HIV in my blood was reduced to undetectable, until today,’ she smiled, and continued, ‘three weeks after I started the drugs until now, it’s been undetectable, and erm, the CD4 count is shot up again to 520, which means erm, I’m responding well, yeah, I’m responding well.’

‘You look happy about that.’ I said.

‘Yeah, actually I do because if it wasn’t for the medication I would have been dead seriously, I know quite a lot of people that died,’
For most of the women as they developed as biological citizens there was an urgency in telling other people about what they had learned and further more to go back home and educate the community there, when their immigration status allowed it. For some the journey towards active biological citizenship and obtaining knowledge has perhaps been a more conscious one. They are taking advantage of the new knowledge and engaging in groups that will provide further possibilities for new understandings. Grace was intentional in her decision to remain in the UK and she talked about how she had learnt to manage her new biological self.

‘My illness has kept me here since the situation back home isn’t settled yet no food, no medication, the water is all that so, plus I wanted to gain the knowledge from a place like this, we, we, whereby there are groups where we go and be taught how to maintain himself like the self management course, like what is HIV, what is the difference between HIV and AIDS, the treatments, how you take them, the exercises that can make you better when you are taking the medication, all that.’

She went further to tell me about the management of the biological self and its advantages, she said,

‘Because my being HIV positive has also made me have the privilege to be screened and to be well maintained’

Like all of the mothers in this study, the benefits of life itself and what that meant to being able to fulfil their role, was the motivation to keep managing their bodies, taking their medicine and attending medical appointments. Medicines most had begun soon after diagnosis. A Foucauldian analysis would call this Bio-power, Grace and the other women as subjects of discipline and the management that she was talking about a ‘technology of self care’ (Foucault, 1994; Landzelius, 2006)\(^{17}\). However, as we shall explore in the following chapter, Grace and her fellow active biological citizens are challenging the traditional powers that would govern them. They are contesting the traditional power

---

\(^{17}\) Landzelius has discussed ways in which these traditional power relations are being contested (2006).
relations and aiming towards empowerment and rights for women living with HIV, not only for themselves but for women even on the other side of the globe.

_Motherhood at Stake: Disclosing to Children_

It is this knowledge that the women have acquired for themselves that they perceive as paramount in maintaining relationships with their children and family. In the absence of the new knowledge it is very difficult for women to maintain their role as mother and may lead them to decide not to disclose to their children or family. Susan talked about the feeling of losing her right to practice the role mother in its broadest sense, soon after she received her diagnosis.

‘I remember feeling so useless [she laughs] 2005, I’d go to the hospital and they sent me to a nurse and she was quite young, in her teens and I was looking at her and I was saying, I’m in my forties and here I am sitting here with this thing and this girl is actually trying to give me advice, I’m supposed to be giving advice to this little girl but she is the one giving, and I felt bad, I felt dirty, I felt, useless.’

Disclosing to their children was a challenging part of the process of being a mother and managing their HIV. Being able to overcome the values of the wider Zimbabwean community that had taken root in their being was a process. Susan told me about her two sons in Zimbabwe and how she feels that she has ‘lost’ the eldest one and the other boy is growing up fast without her. She is trying to fulfil the role of mother for her daughter who lives with her in London and be the ‘pillar’ for her. In the last four years since her diagnosis, Susan has had to balance managing her HIV whilst looking after her daughter. She has not yet been able to disclose to her daughter and said a number of times that she has to be very ‘secretive’ and negotiate various situations. On one occasion during a visit to the clinic the precarious nature of this balancing act was brought home to her.

‘it’s because like [she] is still young, she is still eleven, there was a time when she asked me mummy are you HIV positive because I was sick, taking her to the GUM clinic and
she was seeing all those posters and she was saying, mummy are you HIV positive? And then I said oh my god this girl can read now, I said no,’

Patricia has already become very active within the biosocial field and is an advocate of disclosure, for her it has meant the acquisition of knowledge and becoming strong. Yet, she recalled what it was like to find acceptance as a mother managing and living with HIV and the feelings of loss that she had when she disclosed to one of her daughters that she had been diagnosed with HIV. Her daughter had come to join her in London from Zimbabwe.

‘I think it’s about educating, [She] was a bit funny, I would eat, she wouldn’t want to do the dishes, she wouldn’t want to touch me and then I knew she had the wrong information about HIV, so I started telling her about HIV and until today she is confessing, ‘I used to think people with HIV, they stink, they are dirty’, you know but now they just see anyone . . . and I remember on my birthday she wrote me a card, ‘mummy you are a star’

Later she referred to the same moment and said,

‘I felt so bad, I felt really bad and I thought maybe, she thought maybe I was contagious, dirty and to make matters worse because I had left their father back in Zimbabwe and by the time they came to join me it was about four years later, maybe she thought I was messing about’

It became apparent during this and other conversations that the process of acquiring knowledge that the women had undergone themselves was something they desired for their children and crucial for being able to regain their relationship with them and their role of mother. As ‘body experts’ it meant that the women could educate and label as legitimate the body of a woman and mother with HIV. Constance had found it relatively easy to talk to her children about her diagnosis. She had attended a support group with them that supported and educated children with parents living with HIV. She referred to this as especially important in helping her communicate with her children. For Patricia, the sign that she had regained her role as mother was in receiving messages of respect and affection from her daughter.
Being able to disclose to children is complicated by the ambiguous situations of immigration. It means that the women are separated from their children and unsure about their knowledge of HIV. Additionally, the distance meant that the children could not see their mothers looking healthy and well. In that way it is difficult to bridge the gap between what people experience as the material HIV body and the embodied meanings of HIV in Zimbabwe and the reality of the healthy looking corporeal body of the women being kept alive with medicine.

Grace is a widow and has seven children and I asked her whether she had been able to tell them about her diagnosis. It was much easier for her to tell the children who had some ‘new’ knowledge and could see her face to face.

‘My children back home no, but my two sons who are here they were coming to see me and I told them. So I told them this is the situation so I don’t know how you will take it then both my sons, like me being educated, being in this country for a long time, they’ve seen some friends and other people who have gone through it they just said ‘mum, in this country you are lucky that there is medication there is food, rather than in Zimbabwe where life is tough, we are glad you are here, we’ll see to it that you get all that you need, we’ll ask the Dr to help you through, don’t ever think of death, here you’ll survive’.

It was more difficult to tell her other children,

‘My other five children back home in Zimbabwe, it took me time to tell them because back home once you tell anybody, there’s no HIV there is AIDS always, they will just think mummy’s dying and being far I didn’t want to disturb my children.’

Grace’s asylum claim on medical grounds is still pending after three years of waiting and poses a challenge for her to being able to disclose to her young children in Zimbabwe,

‘if God gives me my papers if I can be able to be going in and out it will, I would rather prefer me going back home and talk to my children on my own, them seeing how healthy I look it won’t make any difference to them because I will just tell them this is the situation but look I been having treatments, I’m well I’m moving on so don’t worry and don’t tell anyone, it’s only for you.’
The fact that Grace hasn’t been able to tell her youngest children is a painful experience for her. Despite the fact that she feels able to manage her own body, her sense of ‘wellbeing’ is linked to how her children feel.

‘Because you know distance can make children think, argh maybe mummy’s enjoying because they are young, like my daughter who had her birthday on the nineteenth, I phoned her and said happy birthday she said oh mum but the problem is that you no longer want to come and see me, you see, because she knows nothing’

**Pragmatics of Motherhood**

The pragmatics of motherhood bears witness to the fact that these women do not live in isolation but constantly consider the needs of their children and how to go about their role. Having enough energy to look after young children and staying healthy enough to be able to see them grow was amongst the daily challenges for these women. Having enough financial resources was also of great concern to them. Of course the financial insecurity was inextricably linked with their immigration status. For those without ‘leave to remain’ it was forbidden to work. As I have already mentioned this really became one of the most pressing worries for the women. Ruth is supporting four children financially back in Zimbabwe. Despite the fact that she is able to manage her own body she told me that that amounts to nothing if you are unable to fulfil your role as mother which results in a troubled mind. She told me,

‘Taking a pill, your body is physically well but if your mind is not well it is not ok’

Apart from challenges of separation to motherhood, for those who have children in the UK there are present concerns. It was a challenge to support children financially in the UK. Susan told me that it was difficult to explain to her daughter that she didn’t have enough money for skinny jeans on the days that she goes to pick up her weekly allowance. Patricia was arranging her Skye TV connection one day and turned to me and said, ‘this is yours Clare, that’s being a mother, I don’t have time to watch TV but my children want it so I have to get it’.
It also became very clear that being a migrant made disciplining their children and fulfilling the usual way of being a mother ambiguous. I heard numerous stories from the women of confusion about how to mother and discipline their children in the new context. The acknowledgement of child protection and rights for children in the UK was difficult to reconcile with their traditional role that gave them absolute authority to discipline their own and other peoples children. There was a fear of the authorities who might remove children if they disciplined them. The fear was echoed by all of the women and shared in the group discussions. Since motherhood was perceived to some extent as the role of any woman and that it took a whole village to raise a child, they felt that this role had somehow been lost because their offer of discipline within the wider society would not be accepted or even allowed. They discussed this together.

‘So the culture here it’s sort of, it’s giving us less authority over children or we can’t maintain the children’, said Grace. Later Giftie added,

‘There is a change, it’s different from back home because here laws, and erm there is laws and rules that guide you and you reach a certain stage that when children are teenagers they speak back and er never could control them, where as back home you wouldn’t speak back to your parents, it, but here they have freedom of speech and the law, the law guides them and allows them, and if you interfere a lot or if you try to discipline them, they get taken away and initially the adults at sixteen they can be put in a hostel.’

Chapter Conclusion

Women come to understand themselves in biological terms and manage their individual bodies. Whilst there is great hope of staying healthy, the reality of a failing material body sometimes surfaces. This management does not remain an individual experience but one that affects their relationship with their children. Some can share the management more easily with their children than others. However, ‘successful’ management amounts to nothing if they cannot fulfil the role of motherhood, which brings great worry.
Chapter 5: Finding Support: Forming Networks

‘To be honest with you Sam, it’s all about getting engaged’
(Patricia)

During one of the discussions at the meeting place in the upstairs room of the house on the river bank, a small group of us talked together about where the women found support. The discussion had turned towards the subject of support when one woman expressed that survival was not just about medication and in fact that the medicine didn’t work without ‘emotional support’. She said ‘when you take your medication in the middle of the night you will fail to sleep, not because of the side effects but because you are ‘stressed’’. She referred to being stressed about thinking about family back home and ways to support them, the greatest concern being how to support them financially. At the beginning of the discussion we had each drawn a social map, our names in the middle of an A4 piece of card and the people who were part of our lives marked around us in different coloured pen, indicating different types of relationships. Amongst the ‘helping relationships’ were support groups, HIV counselling and advice, the health service and social services. All of the women had drawn these close to their name on their own map to denote a high level of importance of these helping relationships in their lives. They had all labelled loving relationships and some close friendships near to their name on their maps as well.

Dialogue about Networks
Nearing the end of the group session, after the discussion had turned to support, Sam the facilitator asked a final question. She asked about where the women found the support that they had been talking about as so important in their lives. Was it within the Zimbabwean community or amongst the relationships that
they had drawn on their map? Patricia interrupted her before she could finish her question and began to describe the way that she perceived the support, something that was not possible to understand from the maps alone. A very exuberant and passionate discussion ensued,

‘To be honest with you these four who you are seeing here now, this is the highest, I mean the, the, the high levelled-’

Rosemary added thoughtfully,

‘Of family’

Patricia continued picking up her train of thought,

‘Of family members of the people living with HIV-’

Sandy said decisively

‘Networks.’

And Patricia continued,

‘We are everywhere, [pauses]-’

Sandy made a sound of agreement as Patricia spoke,

‘Can I be honest, go to . . . ’18, you will find her there-‘ pointing to Rose, ‘go to . . . she is there-’ Patricia said as she pointed to Sandy.

With the volume of the conversation rising, Rose joined in raising her voice to be heard and said,

‘Go to . . . , . . .’

It was difficult to discern the individual voices at this point as they all chimed in reeling off the names of the other groups that they attended, Patricia with a loud and passionate voice said,

‘We are there, where ever, . . . we are there, you see it’s all about-’

18 Referring to other names of support groups
Rose raised her voice again to be heard above the gaggle.

‘Exactly, meeting with the, the MPs, I’m going, I’m going’

Patricia agreed and they laughed out loud,

‘I’ll be there-’

‘The same people we meet everywhere-’ said Sandy,

Patricia began to bring the level of the conversation back to a sense of calm as she looked at the facilitator and said,

‘To be honest with you Sam, it’s all about getting engaged’

And Sandy said emphatically,

‘Yes’

Rose said,

‘Taking back the power’

‘mm, mm, mm-’ agreed Patricia,

Sandy recalled a comment from her sister also living with HIV,

‘That’s what my sister said, fight for your rights-’

Patricia continued,

‘if you will just stick to one you just, you, your resources are limited, your information resources are limited but get bigger networks-’

Sandy agreed,

‘Yes’

And Patricia continued,

‘You get stronger too’
Despite the fact that the Women’s Action Group itself had been a very important source of support for these women, it became clearer that forming wider networks within the biosocial field were paramount for finding support and getting ‘stronger’, as Patricia put it. The Women’s Action Group is part of a larger organisation called the women’s ‘network’ and as the name suggests the forming of alliances and networks was an original intention, as described to me by one of the founders. Sam asked the women about the support that they got from the friends whom they had included on their social maps. There was a huge gaggle of raised voices again as they agreed that their stories could only be shared in a limited way with people outside the biosocial networks of people living with the virus. They recalled the times when disclosure had resulted in losing friends and Sandy even said some of these relationships were ‘dangerous’. Additionally, they could never be certain as to the level of understanding outside the biosocial network and whether people had the sort of knowledge that they had been acquiring themselves. This strong feeling about finding support within the networks made sense when I considered their stories about disclosure and how they had found it easier to talk within groups of people living with similar experiences. They talked about sharing their experiences within the biosocial networks and Sandy said,

‘You don’t choose your words’

Rose agreed,

‘Yeah you just say it, I can just say ‘oh my god today I’m feeling so crap’, ‘what is it?’, ‘oh the pain medication’”

Patricia cackled out loud, a flash of recognition and the two made a high five and laughed. They all agreed that they were a family and then the conversation descended into excited gossip about the ‘Miss Uganda’ competition that was coming up and who would be attending.
Forming Novel Relationships

This dialogue represented how the women found consensus as active citizens in forming networks and their identity as family. They were gaining knowledge about their own condition and fighting for their own rights as women and biological citizens. They were fighting for the power to make their own voices audible as women living with HIV and to be able to remain in the UK and continue medication. Patricia had identified the group as ‘family members’, explaining the new forms of social relations that were developing in the biosocial field. It made sense that ‘new’ kinship relations were being formed since the women needed to gain resources in this new context in the absence of the ‘normal’ kinship relations that they would usually draw upon. Additionally, they did not find it easy to disclose their status to just anybody and the Zimbabwean community in the UK, which could be a potential place of support, often represented an unsafe place. It was difficult for some of the women to share it with their own families and children. In the context of ‘therapeutic citizenship’ in Burkina Faso, Nguyen describes these new forms of social relationships and communities as ‘bricolages of pre-existing social relations (such as kinship relations), global therapeutic strategies and local tactics’ (2005:129). He argues that in the new context these communities ‘recapitulate earlier attempts to translate kinship into strategies for accessing and redistributing resources during colonial modernity’ (Nguyen, 2005:129). In the context of London, I would like to suggest that the women were part of a similar process. The Zimbabwean colonial history perhaps makes the comparison a more pertinent one where these women know what it is to negotiate resources. Rose had once told me when we were discussing social relations, ‘I grew up in a colony so I know how these things work’. The women have formed new relationships that offer them access to resources such as support and knowledge, a ‘voice’ that makes it possible to access their own acquisition of power. I perceive that this is exactly what the women were trying to tell Sam and me
when Patricia described that with larger networks they had broader resources and they got ‘stronger’. By situating themselves in the biosocial field and making strategic networks the women could access both cultural and social capital. Capital that would aid them in their cause of ‘taking back the power’ and ‘fighting for their rights’. To take the concept of new kinship relations a little further, I perceive that these women have become the ‘matriarchs’ of the new community of women living with HIV in the biosocial field. They are the matriarchs for women just beginning their own journey with HIV and in need of guidance as they begin to negotiate their new situation.

The remaining group of women had been less passionate when we discussed support in the same upstairs room of the river bank house a week later. Nevertheless I heard a similar story from them as they discussed together about finding support from within the biosocial field and a fight for power. Giftie talked about finding her support in the support networks and that she didn’t talk to ‘outsiders’. Susan recalled her stories of rejection and how she had decided to deal with her HIV diagnosis within the group. Constance had had a very positive experience of having medical and social support right from when she was pregnant with her son and was introduced to support groups. She said that she doesn’t usually talk about her health status with people outside the groups. Giftie reflected on the empowerment and rights that they had gained within the network during their journey and considered the situation of their counterparts back in Zimbabwe,

‘I wish women back home would be empowered with the knowledge and with all what we are getting here so that they have the knowledge of their rights whether they are HIV or not because back home they don’t even know, they think it’s the end of the world for you and they are not empowered at all’

In an earlier conversation when we had talked about what it would take for women in Zimbabwe to acquire a ‘voice’, I had pressed Giftie to explain to me
what she envisaged when she used the concept of empowerment. We had laughed as she commented that I had given her a headache with all my questions and that she would need a dictionary to explain it to me! She explained that it was about ‘equipping, supporting people so they can do the things for themselves, you know doing it for themselves but supporting . . . educate, empower with knowledge’. When the others raised the concept of empowerment there was a strong association with knowledge about their rights as women and people living with HIV. Grace had described it as ‘getting knowledge’. Constance had said that it was about ‘getting strength’ and how she had ‘got empowerment from other women’ through sharing experiences. Ruth had said ‘it’s being able to stand up for yourself, be able to say no and to ask questions’. As they talked about how they had been empowered I detected the discourses of a ‘moral economy of hope’ that demanded this empowerment for other women.

I pondered all of these discussions and detected the strands that I had been trying to reconcile throughout my time with them. It was clear from what Giftie said that the women had undergone a transformation, a process that entailed a lot of knowledge acquisition. By engaging in networks they were being changed. Their collective story spoke of what it was like to be without voices and that they had been on journeys of acquiring new knowledge and liberty, knowledge that gave them a shifting sense of their own identity. Yet within the stories were frustrated voices that, despite this ‘empowerment’ there was still a long way to go in the journey of being able to feel completely at ease with their situations and their bodies and eventually being able to challenge the expectations put upon them as women. They were not yet able to be truly independent. They were still constrained to an extent by their collective history and the habitus that would subordinate them and make them feel unworthy and prevent them from talking about their experiences as women with HIV. These
things were made present to them largely by the wider Zimbabwean community around them in the UK which found it hard to accept their diagnosis. Some also found it difficult to share their journeys with their families back home in Zimbabwe. The reality of uncertain immigration status was a crucial obstacle to their liberty. The ambivalence of these women’s experiences was evident, being empowered to an extent but still desperately wanting and needing to ‘fit in’ outside the support group. I detected the hurt and frustration of having to ‘hide’ but they were still fighting and educating and wanting to empower others. They were agents of change within the biosocial networks, forging their identity and accessing the political level as well. By representing the matriarchs and possessors of knowledge, they were setting an example to others who might join the group and wider biosocial networks, thereby forming their own identity and securing the identity of the social world in the future. Bourdieu considers the ‘contribution that agents of change make towards constructing the view of the social world’, ‘by means of the work of representation’ that they perform in order to impose their ‘social identity’ (1985:727). However, there was still a long way to go to acquire their total liberty and it is something they have to do together. Sandy had said to me, ‘you know what, its war, we have to fight together, the only thing that hurts me is being blamed for it.’

**Acquiring Resources**

So what exactly are these resources that the women were acquiring through engaging in networks and what do the women use them for in their choices about motherhood? As the women acquired resources for themselves and became empowered, they sought to share them with other women in a similar situation. Forming networks was not just about finding support but it was about fighting for their rights and taking back the power for others and empowering women at large. Within this ‘moral economy of hope’ these active women felt that it was their responsibility to share resources and pursue the
rights of other women in the biosocial field. As members of the biosocial field they were operating within new complex ethical dilemmas that emerge and negotiating and demanding resources for themselves and their counterparts. Rose and Novas identify the role of support groups in engaging in these dilemmas (2005). They are fundamentally fighting for the right to be able to be kept alive but also the right to be able to make choices as women, to have children and be mothers. This is a deeply ethical dilemma, especially in the age of HIV and a whisper of a future debate that will most likely take place, if it hasn’t already begun and one that we will revisit in the final chapter.

Following my theoretical perspective on the body I turn the gaze to how Bourdieu described the body as a form of physical capital and that these bodies populate a certain social field (1985). In my own analysis I perceive these women as situated within the biosocial field, having acquired a certain amount of social capital. In their role as matriarchs they possess a certain amount of capital such as ‘power, status and distinctive symbolic forms’, which can be converted into various resources (Shilling, 1993:127). I argue that it is by finding their place within the biosocial field as active members and ‘matriarchs’ that these women are able to acquire certain forms of capital for themselves. The forming of networks represents a form of social capital that provides support and ways of getting services. As Rose had said they broadened their networks to the political level and met with MPs and were able to discuss issues around migration and HIV policy19. This related to what I had heard about the early days of the Women’s Action Group. They had intended to use the HIV issues to ‘leverage’ the other social issues that were emerging; the most pressing one for the women being the acquisition of a secure immigration status. These women also acquire cultural capital within the biosocial field, which is knowledge about

---

19 The African HIV Policy Network (AHPN) is a good example of connecting with a policy level. Women can voice their opinions and sometimes be present in campaigns in order to be heard in a wider political arena.
HIV and their own rights and enables them to shift their own understanding about themselves and pursue these rights. Furthermore, they experience the possibility of being a woman possessing a voice. This knowledge is used to develop ideas about alternative ‘symbolically valued bodies’, for example women without children. There are some forms of economic capital available for the women. Without leave to remain they are unable to work and can receive small financial ‘incentives’ for taking part in certain groups and workshops in the biosocial field. These forms of capital, especially social and cultural inform the women’s choices about pursuing motherhood.

**Acquiring Capital: Becoming Pregnant**

The women had been used to seeing babies being born with HIV back home in Zimbabwe. It was only on entry to the biosocial field, after their own HIV diagnoses that they discovered alternative possibilities. They learned of the way that women living with HIV could still fulfil the role of mother. During the same dialogue that we discussed at the beginning of the chapter, the women spoke of this acquisition of knowledge and their role now as active biological citizens in sharing the knowledge with others and ‘empowering women’. I learned from the women that it has traditionally been the role of the aunts and uncles in the Zimbabwean community to ‘educate’ the teenagers and young adults about sexuality. It appears that these women, as matriarchs are taking on the role of ‘aunt’ in the re-worked kinship relations in the biosocial community. Sandy said that she felt there had been a loss of the opportunity to become a mother when she was first diagnosed,

‘in the beginning I think, yeah, first thing that came, yeah, it’s because like back home I had seen a lot of women who had given birth to positive children and it was painful, it was so painful and you think why did they give birth to these kids? Why are they punishing them? It was such a strong one, and you think to yourself why am I going to punish an innocent soul? But then with, then because of education, knowledge and then open advice they tell you no, no, no you can have negative kids, it’s all good, I know of a lot of women who have had negative kids-’
Patricia said, ‘it’s all about education’, Sandy agreed and Patricia added with astonishment,

‘but do you know, do you know that even today in this country I’ve come across, with this work anyway, I’ve come across quite a lot of couples who, not couples individuals who think because they are HIV positive now they can’t have any more babies . . . I’ve heard quite a lot of them until I had to educate them, educate them, educate them, now they understand, oh I feel that’s my job’ [laughs]

Sandy agreed, ‘it is your job’ and Patricia continued,

‘oh I can’t have a boyfriend because ee with this HIV agh let HIV not be a barrier to your sexual, I mean relationships, you know love life, you know, then I give them examples to be honest . . . don’t deny your womanhood’

She added later, ‘you know what I think it’s all about educating, like what, you know what I was saying like with the four of us, yeah, because we have been so much into this business for a long time, now our minds are.’

Sandy said, ‘are broadened’

‘Yeah’ agreed Patricia.

These women have been on a long journey and discovered opportunities that are available with their acquisition of knowledge and other resources. Within their discussion they were reinforcing the roles that they had constructed for themselves within the networks. They have taken on the role of ‘matriarch’ and ‘body expert’, which teaches and empowers others. They become the moral pioneers in seeking the rights of women to become mothers (Rose & Novas, 2005).

For both Joy and Sandy who do not yet have children, the possibility of being mothers is open to them from a biomedical perspective. They are supported by the biomedical field and have undergone the acquisition of knowledge. Joy told me how her consultant is ‘just like her ‘aunty” in the way that he wants her to become a mother! In the same way Sandy told me that her consultant raised the issue of motherhood and encouraged her to think about it too.
“if you do decide to have kids you can come in, we’ll sit down and talk about it and we can make plans about what is the best way for you’. So probably that is not the only way my friends have told me, probably there are other ways they can, you can still have babies, because my consultant did say, ‘the day you are ready to have kids, come in and we can sit down, and we see what’s the best way we can take’, I said ok, not a problem [laughs] will do’

However, this is not the only support that is needed other than the loving relationships that we have already discussed. The women who had been used to seeing babies born with HIV needed to see how the pragmatics worked. Sandy was referring to some intriguing stories of ways of conceiving that some of her friends living with HIV had experimented with. These creative ways included large syringes in place of sexual intercourse. Some had become pregnant and had healthy children. She said,

‘For me, I have the advantage of live people, real examples whereby I can fall back on and ask questions and they can give me ideas’

She realised that her consultant was offering a more conventional way of conceiving but it was seeing the ‘successful’ mothering of her friends and healthy babies that was important to Sandy.

‘I think meeting up with other positive women they’ve got family and good looking husbands and they are still having a good time’

These living examples from women within the biosocial network (social capital) were a resource that contributed to the way Sandy and Joy were thinking about and making choices about becoming pregnant for the first time. Where as in Zimbabwe they would have called upon aunts to advise them about sexual matters, Joy and Sandy were finding their resources amongst women and friends within the networks, the re-working of kinship relations. By putting themselves within the biosocial field, becoming ‘family members’ and engaging with that world they were able to ‘convert’ what they had there into social capital where they could ask questions and find support. Joy had a similar story of acquiring
social capital. Although there were not specific teachings or advice within the networks about becoming pregnant she said she learned from those around her. In the early days of her diagnosis she had been part of the meeting place by the river.

‘You know it’s, the support groups, what I did find was the you know, like you know at [the group], I remember going to [the group] and you know seeing, I think there were two pregnant women and you know they did give birth you know to negative children and they grew up literally while I was watching at [the group],’

Joy is now herself facilitating workshops and discussions for people who have just been diagnosed with HIV and she says that there is very little emphasis on sharing information about getting pregnant and PMCT. She thinks that this is something that should be added and she is in fact campaigning ‘to get the manual changed so that it includes mothers and children’. She was the youngest woman in the study and looks like she is forging a way ahead for the rights of women living with HIV to become mothers.

**Acquiring Capital: Having a Baby**

Giftie found support from within the support network of the biomedical field when she became pregnant. She referred to her understanding of the situation in Zimbabwe where there was very little adequate provision for pregnant women and their unborn babies as a factor that lead her to try to interrupt her pregnancy. It was the support from the medical field in the UK that she was already receiving and the acquisition of new knowledge from within that field that enabled her to make a choice to go on with the pregnancy. She explained that this was in stark contrast to the experience of a woman in Zimbabwe, the structural factors, compounded by the troubled political atmosphere. She told me,
'I tried to get rid of the pregnancy and in the end I had to think very, very carefully about it because having that support I was having (from) the support network you know professional support network (from the hospital) there was possibility for the child to be born negative (I learnt that) while I was here, yes, but if I was back home, definitely I would have terminated it with no doubt. Because we have a belief that back home once you have a child you go down, you get ill because of that, of having that child, so you will die, and instead you bring that child into a life they didn’t ask for and they’ll be ill all the time and there’s no consistent medication, no blood taking, no checking on them because of the political issues back home in Zimbabwe,'

Constance received her HIV diagnosis during routine antenatal testing in London. Due to difficult circumstances in her life at the time, she was already eight months pregnant when she received the diagnosis and began medication for PMCT. She lived in a special mother and baby unit for five months after giving birth to her baby who is not infected with HIV. Apart from the support from medical staff, she said it was very important to have other mother’s around her in the same situation.

‘yeah we used to talk, share ideas, share stories, you know, because most of them had post-natal depression, yah after giving birth you know they would break down em’

**Acquiring Capital: Being a Mother**

It was clear too that the networks and groups were a support to the women in their own journey as mothers. Rose had commented once about that.

‘you know how we have those, they seem like silly nonsense type things, like when you, you know when we meet on a Friday and we do our sewing and we talk about the kids and we sing and we do stupid things, just that, you know, holding each other’s hands through stuff, that, that’s what keeps us going.’

The issues that we discussed about the pragmatics of daily motherhood in Chapter four were shared in the group. It was being able to share the everyday struggles of motherhood that gave the women resources to negotiate their roles and find out how to be a mother in this new context. They did discuss how their roles as mothers were changing too and that they perhaps ‘mellowed’ as they got older and were less strict with their younger children. During an interview with
Constance she told me how she had found support within the Women’s Action Group to help her in approaching motherhood and how they could discuss issues together,

‘especially bringing up children in this culture, because it’s not like back home cause children here they’ve got their rights you know their own rights you know, I’ve got this rights I’ve got that rights you know you can’t tell me this, I’ve got to do this, you know and then you learn from other mothers how they deal with such situations you know especially children who are teenagers it’s so hard for a teenager in this country I think cause they are exposed to a lot of things’

**Immigration & Social Capital**

The resources to be acquired were not just about finding support for daily experiences but a very pragmatic goal of being able to obtain the right to stay in the UK and a clear immigration status. This is really what was at stake for all the women that I had met regardless of their individual situations. Those who had already received a status had shared in the ambiguous journey. There was a need to employ particular resources in order to obtain the social capital and ultimately entry into the national citizenship. Patricia’s story of being granted indefinite leave to remain is an example of how she used evidence of her involvement in networks as a resource to accessing entrance into national citizenship. She had taken a file to the Home Office full of ‘evidence’ of the things that she had been part of since her arrival in the UK, certificates, photographs, reference letters from the organisations that she had been part of. She talked with utter delight as she relayed the story to me of how the officials ‘couldn’t believe it’ as she presented the great tome to them. By engaging in networks, she had been able to acquire capital that was being used to negotiate her place and acceptance into wider citizenship in the UK. The Women’s Action Group had made it very clear from the outset that they were looking to leverage the social issues in the lives of these women. They have helped somewhat in
fulfilling this for Patricia. Amid the challenges of negotiating social fields in order to find support there is an emerging power, a politics of vitality.

Chapter Conclusion

Forming networks is necessary for survival and making choices. By engaging in the biological field and accumulating ‘physical capital’ individuals can convert it into both social and cultural capital which assist in survival. The cultural capital of knowledge was very important to the way the women understood their own situations and futures. The acquisition of knowledge is something that empowers women. It gives them freedom but also understanding about their rights as women living with HIV. Thereby enabling them to transform understandings of who they are and a shifting habitus. The social capital of forming networks meant that they could find support from the social body in making pragmatic choices about their lives. These choices include those about entering sexual relationships, becoming pregnant and being mothers. Small amounts of available economic capital help women who are often struggling financially. Novel relations emerged in the biosocial field. The women in this study forged roles for themselves in the new biosocial field as educators and vessels of knowledge, in a way as the matriarchs. They hope to empower other women who are beginning the journey that they have been travelling. The value of networks is high especially illustrated by the fact that women have the potential to have their voices heard at a political level and may even be able to achieve their greatest challenge which is securing the right to remain in the UK. It has been a clear intention of the women’s organisation since its inception to enable women to form networks that assist them in building a future. Rather than becoming subject to biopower these women are contesting traditional power relations and developing networks and demanding that their own and other women’s voices be heard.
Chapter 6: Conclusion: Moving on

‘I like using my hands a lot, be sewing, knitting, and also discussing about our family problems, it’s a place where we are free to talk to help each other, ideas of how to move on, somebody who has got immigration issues, we come, we talk over with them, if we have any housing issues we come and ask any help,’

(Grace)

This research has traced part of the journeys of ten women as they have migrated to the UK and begun to negotiate a new set of circumstances in this new context. It has been a process of discovery that has conferred new understandings about the way that they relate to themselves and their own bodies as Zimbabwean women and mothers. It also traces the way that they relate to the people around them. The study has identified the moment of diagnosis as a crucial one and explored how the women have come to terms with and manage their HIV in the context of relations with their children and family and indeed the wider society. It traces how they have found support in the Women’s Action Group, somewhere that intends to provide a safe space for the women to share their journeys and their struggles. There are also possibilities for the women to engage in wider networks as they become active biological citizens, acquiring knowledge, getting stronger and in the process, contesting traditional power relations.

Diagnosis & Management

All of the women in this study received their HIV diagnosis after arriving in the UK. It marked a crucial moment in their lives and a point where choices needed to be made about whether to return to Zimbabwe and be reunited with family and children or to remain and receive life saving treatment. For most, receiving a diagnosis was a shock largely to do with the meanings that are attached to HIV in the Zimbabwean community both in the UK and back home. However, at the moment of diagnosis these women enter a world of biological citizenship and as
such have begun to acquire new knowledge about their diagnosis and their own bodies. They begin to relate to themselves in new ways as they come to terms with their diagnosis and find ways of managing their own bodies. This was a process accompanied by hope for the future. As this shift takes place the women are able to negotiate the meanings associated with HIV with which they had been familiar. I heard from the women that in Zimbabwe, AIDS is so often associated with death and morality. As a mother living with HIV you have failed. In this study a sense of being a moral failure was not near the surface when I spoke with these ten women and part of their perception of their own self. This is contrary to what Doyal and Anderson describe where the ‘feelings of stigmatisation among those infected with HIV’ are exacerbated for mothers expected to be ‘moral guardians of society’ (2005:1732). The sense of losing their right to be a mother because of living with HIV came at the moment in the past when they were diagnosed. With the acquisition of knowledge, which gave them new biological insights and understanding about themselves, the sense of feeling ‘dirty’, ‘useless’ or ‘contagious’ faded away. Their bodies were not receptors of the social discourses that other studies have pointed out but dynamic and seeking out new ways of seeing (Lawless et al, 1996). The meanings associated with HIV infected women’s bodies were a social construction that had been ‘inscribed’ to an extent. However, by engaging with new explanations and knowledge, these women have been able to find alternative meanings. The women do not experience their own HIV diagnosis in isolation. Individual bodies are experienced within the social body and while they have been able to acquire new understandings about themselves they have struggled to share them and find acceptance within the wider social body outside the HIV networks. These struggles are born out in the way that disclosure to their own children and the wider social field is a challenging journey where they risk rejection. At this point in their journey their bodies have the ability of passing as ‘normal’ within this wider social field and the
women are careful about how and with whom they share their experiences. Motherhood, being and becoming a mother, and their status as women are at stake and they often decide against disclosure in order to survive socially. This struggle traces the deeply entrenched notions of HIV. For most women, being able to share their new found knowledge and understanding about HIV is crucial to being able to find acceptance.

Whilst treatment and a wealth of new knowledge and support from biomedicine is available to these women in managing their HIV diagnosis, securing a definite immigration status has been a struggle and one that began for most at the moment of diagnosis. Having HIV does not necessarily confer compassionate acceptance into national citizenship and the women must draw on other resources to achieve it. This struggle has shaped their experiences of being women and mothers living with HIV. The failure to secure their immigration status threatens to bring to an end their treatment and chance of survival and prevents the women from being able to move on. This struggle continues to be part of the daily journey of over half of the women in this study. The others share the experience of having been through this arduous journey.

Finding Support in the Women’s Action Group
The women in this study are all connected with the Women’s Action Group and are united by the fact that they are from Zimbabwe and share uncertain immigration issues, a positive HIV status and the particular cultural expectation of proving themselves as a woman through motherhood. The Women’s Action Group has been a place where they have been able to share their struggles, their journey and their resources. As Grace said, they have been able to share the problems and issues of daily life and help each other with ‘ideas of how to move on’. They have learned together about their diagnosis and ways to manage it, how to disclose and begin to move on. It has been part of the process of
acquiring new ways of seeing themselves and contesting the discourses that would render them unworthy. An early intention of the group was not only to focus on the issues of HIV but also to advocate for women as they adjusted to a new context and put pressure on the ‘social issues’ that were emerging including the immigration issues. At its inception the founders were aware that the process of socialisation had made it difficult for women to feel worthy without fulfilling the role of mother and that the ability to fulfil it in the new context is challenged. As such they have a focus on women’s rights and acknowledged the need to form alliances to work more effectively for their cause. The women acknowledge that they need to form networks in order to acquire more resources and strength.

Engaging as Citizens

It was their resilience and ingenuity to acquire knowledge and power and in negotiating the social field and forming networks, that was so impressive about these ten women, something that has not been discussed in other studies of migrant African women living in the UK. I had originally wanted to find out how experience of the individual self influenced choices about becoming a mother, being a mother and finding further support as HIV positive women. Within the biosocial field of women living with HIV, there is a shift in identity and the biological citizen, comprising partly of the biological self, is born. In this new world of biological citizenship I argue that it has been made possible for the women to make choices and redefine what it means to be human and survive. Opportunities to acquire further cultural, social and economic capital are possible through engaging in wider networks and the women are, as a result assisted in making choices about being and becoming mothers and in taking hold of their rights as women. The acquisition of capital has enabled women to find ways of giving voice to their other social struggles associated with being migrant women living with HIV. Some have even been admitted to enter national
citizenship as a result of showing their engagement in networks and for those ‘legacy cases’ still waiting, this represents a real hope that their engagement will work in their favour in pending claims.

Within this citizenship of hope where the women can manage their bodies and move on, there is also uncertainty about their children, families and futures. The moral economy of hope means that these women as active biological citizens do not succumb to the challenges that they face but rise to them. The experiences and capital acquired through forming networks in the biosocial field can be used to negotiate these challenges and new forms of power emerge for active biological citizens. These women are contesting power relations. A traditional analysis of medicalization may stop here and leave the women as objects of biopower, where their bodies are subject to biomedicine. However, whilst their bodies, as biological citizens, are engaging in a biopolitical complex, these ten women refuse to be objects on which certain ideals are inscribed. They have become empowered as biological citizens through the acquisition of knowledge, formed networks and have moved to a space that enables them to question their historical habitus and discover new possibilities for themselves and others. Their bodies are perceiving, experiencing and engaging in new ways of seeing that give them novel ways to understand and relate to themselves and others. Indeed, biological citizenship is not just about acquiring knowledge for themselves, it is ‘biosocial’. These women desire not only to achieve resources for themselves but for other women who may be in a similar situation. As they engage in networks, they negotiate their role as ‘body experts’ and ‘matriarchs’ who desire to empower and help other women with the new knowledge that they have acquired who may just be beginning their journey as a biological citizen. I argue that these ten women, as active biological citizens are making

---

20 Foucault refers to individuals as ‘biopolitical reality’ subject to ‘medicine a biopolitical strategy’ (1994:137).
use of medicine and resisting the traditional discourses that have subordinated
them and labelled them as unworthy. In a discussion about women and AIDS in
Africa, Schoepf has perhaps provided us with a useful prophecy, recognising
how discourses have more often than not represented the bodies involved in the
epidemic as female (1998). Schoepf recognised that the perpetuation of such
discourses depends on power/knowledge relations (1998). Whilst the political
discourses surrounding AIDS has ‘inscribed the body politic on the body of
(African) women’ there emerges at the same time ‘new forms of both
medicalization and resistance’ (Schoepf, 1998:120).

The Future of Biological Citizenship

It seems that the pursuit of motherhood will continue to be a longed for role of
Zimbabwean women living with HIV despite the challenges that they face in
fulfilling it. Having said that the importance of motherhood has grown out of a
history of gender inequality it may seem somewhat regressive to talk about
women becoming mothers. However, the discourse that arises from the women
is one about choice rather than duty. I perceive that the women will exercise
their power as active biological citizens to negotiate that choice for themselves
and other women. They have already started doing it by teaching other women
about the possibilities of entering sexual relationships and becoming mothers to
healthy babies in the UK. Within this biosocial field there will be more to
contest in the world of biotechnology. I heard stories of women in discordant
relationships, where usually the woman is HIV positive, who are already
circumventing the biomedical world in creative ways in order to become
pregnant. However, there are others who may want to pursue a more
conventional road and find help within biomedicine in order to conceive. In my
interview with one of the women who set up the network, she highlighted how
some women are just giving up when it comes to fulfilling the role of
motherhood, unable to find loving relationships. She said how these women
should be given the choice to get help through IVF. In all my discussions there has been a much stronger emphasis on choice rather than on offering an alternative symbolically valued woman as complete without children. One of the founders of the group had also discussed it. I imagine then that this debate within the area of sexual and reproductive rights (SRR) will be carried out by active biological citizens. Rayna Rapp describes individuals ‘facing complex reproductive decisions brought about by technology’ as ‘moral pioneers’ (Rose & Novas, 2005:450). Rose and Novas themselves extend this idea and envisage active biomedical citizens instead as ‘ethical pioneers’ (2005). These citizens are ‘pioneering a new informed ethics of self – a set of techniques for managing everyday life in relation to a condition and in relation to expert knowledge’ (Rose & Novas, 2005:450). These were not discussions that I was engaging in to a great extent with the women in the study since they each had come to a place where they could largely make choices about their own sexual and reproductive rights. These women are in a unique position though, as Patricia told me during a FGD, ‘because we have been so much into this business for a long time, now our minds [are broadened]’. However, I perceive that as biological citizens and the matriarchs of the new kinship relations and with their desire to educate other women about their rights they may well engage in such a debate in the future. It was certainly an aspiration of one of the women who began the group and her hope that other women’s support networks would engage with the issue.

‘a lot of women have either just given up on motherhood, they have run out of time really, they hadn’t found the right relationship that would enable them to fulfil that motherhood role that they so much desire, however, there are those who are finding loving relationships they would be having children, one, two, three children, healthy children with the advent of medication so for some it’s been (sad) I think it is something that they will regret for the rest of their lives, it is quite sad really, you feel that you have been denied something that completes you as a woman, because most of them have had those expectations . . . I hope that as women’s organisations we can advocate for them to go and have babies through IVF, it should be made available to them, they should have that right, something that I hope that women’s organisations are working towards . . . yes, I mean if you think it, women who have IVF they can have a choice so why not
anybody else who would want to have that choice, why shouldn’t they, but I know that it is something that nobody sees as acceptable because immediately is thought of putting a child at risk or (left without) their parents one day in the future but things have moved on now, we need to see a change, we need to see fairness and justice to women with HIV so we can fulfil their motherhood so that they can have that choice like every other woman has’

This fight will aim to help the cause of the women who didn’t feature in this study but of whom I have heard, from the ten active citizens. Women who have just begun their journey or ones for whom the social pressure of their traditional habitus confines them and the idea of sharing their diagnosis is just too hard. It is clear that there are many women who do not enter this world of biosociality and who have been hidden from the gaze of my own research. An early essay by Scheper-Hughes is perhaps relevant to their futures, where she argued for approaches to AIDS prevention that extends rights to the most marginalised (1994). Her example was those lacking full ‘sexual citizenship’, including ‘heterosexual women who are not IV drug users or sex workers’ and are often left out of discourses (Scheper-Hughes, 1994:992). ‘Sexual citizenship’ meant ‘individual, political, social and legal rights designed to protect the autonomy, bodily integrity, reproductive freedom and sexual equity’ of women (1994:993). She argues that women are often excluded from the process and it appears that there is more to be done in the context of the women who did not appear in this study but who will perhaps be and are already being reached and advocated for by the active biological citizens.

These ten women represent a unique group amongst migrant Zimbabwean women living with HIV in London. Their stories represent a specific moment in time. They are moving on and finding ways of reworking the power dynamics. It remains that these women have found a way of being and sharing together, they have formed networks to help themselves and others. It has been a journey of acquiring a new sort of knowledge. With the acquisition of this knowledge they have been able to negotiate their role as and hopes to become mothers and
contest existing power relations. New kin relations have been formed and they have become the matriarchs of the new family of women living with HIV. There are many who haven’t started the journey and the active biological citizens are trying to raise awareness and include them too. They want to achieve rights for others as women living with HIV, as Zimbabweans and as mothers being able to take hold of the things offered to them in the UK as biological citizens. As such they enter a world of ‘complex biological assemblages’. In the face of challenge these ten women cherish their dreams and fight to acquire liberty that will make the fulfilment of them possible and the journey continues for them. The new symbolically valued body seems to emerge as an empowered woman, able to stand up for herself and make choices in the pursuit of motherhood, whether they be in achieving sexual and reproductive rights for the future or in her current role as mother.
Appendix

Situating Myself in the Research

The HIV/AIDS pandemic has become a truly global phenomenon and decades after its inception old things persist and new issues arise. Its history alone shows that this virus has somehow caught the collective imagination on a global scale making space for the construction of its meanings in different contexts. Nowhere else has this been more marked than on the continent of Africa. Although an anthropological analysis may favour deconstructing the links between AIDS and Africa, it is important to remember that ‘Africa had the worst epidemic because it had the first epidemic established in the general population before anyone knew the disease existed’ and as such is worthy of attention (Iliffe, 2006:1). My own fascination with Africa began as a child when I was told stories and shown old photographs that my mother had recorded whilst working at a hospital in a difficult to reach part of Zambia (formerly Northern Rhodesia). My own perceptions of this very different place were rather exotic, with stories of my mother listening to long players under big starry skies, Rachmaninoff soaring over the African Plains, long car journeys through the Congolese pedicle in a Land Rover to buy provisions, the scent of the milky yellow frangipani and the indigo blue Jacaranda tree, not to forget the romantic advances of the visiting astronomer. However, the most profound story that I remember was my mother’s puzzlement at the incongruity of the enormous, stone built Victorian style Church rising up in the bush on the edge of the escarpment. It planted a seed that I have wondered about ever since. What happens when very different worlds meet each other and what are the consequences if they do not try to understand how they might see the world differently and how they relate to one another? This part of the world has undergone its own historical and social change since the 1960s and had its own place in the story of the HIV/AIDS epidemic. I was able to journey on the red earth road that cut through the
Congolese pedicle, still incredibly pothole filled and visit the escarpment and see the old church looking out onto the enormous plane below. It was in Zambia too that I met a school teacher who was eager to learn from me about HIV/AIDS and how he could teach the children growing up in his township. I complied, somewhat reservedly because I think deep down there seemed to be a lack of fit between what I truly understood about that context and the rather neat way in which what I had learned about the disease considered the solution to be. I had considered going back to that part of the world to answer some of my questions. However, having spent most of my career so far working for the NHS as a nurse in London caring for many men and women from sub-Saharan Africa as well as other migrant communities, my own home turf had generated its own set of questions. Much of the work that I have done with the women has been in the context of HIV/AIDS. To have the opportunity to go back to London and spend the field work time and talk to women about their experiences was a wonderful opportunity. In an often overburdened NHS finding time to try to truly understand the contexts of individuals was just not possible. I decided to pursue the field work outside the limits of the hospital to glean what I hoped would be a greater insight into the social context and relations of the women. Going back to my old ‘home town’ also gave me the opportunity to enter the field not as a complete outsider, although as I have described there were many ways that marked me out as one. There were advantages of understanding how the NHS works when it came to talking with the women and it made it easier to contextualise their stories. On the other hand being an outsider within the group meant that perhaps I didn’t take certain things for granted and would probe more spontaneously and deeply as a result.

**Some Notes on Methodology**

In order to answer my study question specifically I chose to do a qualitative ethnographic study based on qualitative methods. This study can be considered
as an exploratory\textsuperscript{21} one as defined by Hardon (2001). It aimed to gain insight into the experiences surrounding motherhood for HIV positive migrant women by taking an emic\textsuperscript{22} perspective of the participants involved. As a qualitative study this research aimed to gather in-depth insight into the study questions. As such, it does not purport to generate conclusions that can be automatically generalised. Despite the fact that this research aims to take into account the wider social and political contextual factors of the individual lives, the time restraint makes it impossible to carry out a ‘comprehensive’ study. Instead the priority was to gather data about individual experience and their engagement with the social body and is as such a ‘focussed’ study (Hardon, 2001). The study was focussed on the micro-level and took into account the macro level as important contextual experience. I began with my own questions that were informed by the literature review during the planning process. The design of the study was partially participatory research since it accounts for the voices of the women taking part and my instruments were to be informed by them throughout the course of the fieldwork (Hardon, 2001). As such I emphasise that the research reveals in-depth, ‘information rich’ data and understanding about the ten women taking part in the study in a particular context at a particular point in time. As a result the research methodology does not focus on the ability to generalise findings to larger contexts although it may be useful in informing future research design.

\textit{Data Collection & Access to the Field}

My gate keeper was a Zimbabwean woman living with HIV who was very well connected in the Women’s Action Group and the wider Zimbabwean community. As a biological citizen herself she has become aware of research

\textsuperscript{21} ‘An exploratory study is a small scale study of relatively short duration which is carried out when little is known about a situation or a problem’ (Hardon, 2001:178)

\textsuperscript{22} An emic perspective ‘seeks to understand how cultures look from the inside’ from the point of view of the participants involved (Nanda& Warms, 2007)
and taken part in a number of projects. We discussed the aims of my research and I had prepared a document explaining it that she was able to circulate amongst the group. The sampling was maximum variation sampling and as such the women represent a wide range of variation within the parameters of my research (Hardon et al, 2001). The women were to be Zimbabwean living with HIV with or without children. My gate keeper made it possible to get in touch with most of the women within my first week of being in London and arranging all of the interviews within the first couple of weeks of the six week field work. This was invaluable as time was short. She was very keen to open doors for me and as I got into the swing of the research said, ‘Clare, I love it when it just flows’. By virtue of the fact that the study took place in a group that catered for women with HIV the sample were to an extent self selected, however, this has proved to elicit interesting context specific results. Furthermore, the gate keeper had her own position within the group and as such will have had some influence on who agreed to take part. The in-depth interviews with ten women were designed to gather information about the meanings of motherhood and individual experiences (Green & Thorogood, 2004). They were semi-structured and as a result had a high degree of flexibility to explore the emic perspective. Each interview took its own path but always included the ready prepared questions which proved to be very informative. I used a rapid appraisal technique of social mapping to generate discussion about social networks (Aids Alliance, 2009). These proved to be a very useful complement to the focus group discussions (FGD) and although not necessary to generate discussion it was a useful talking point. I carried out one in depth interview with the woman who was involved in setting up the group which was designed to give insight into some of the contextual factors in which the women were living and the intentions of the organisation. The two FGD were carried out at the end of the research including the ten women who were taking part in the in depth interviews. Four women turned up for each group, a good mix organised in
discussion with my gate keeper. It was designed to pursue the themes that had come up in the in-depth interviews and acted as a way of testing ideas that I was formulating (Green & Thorogood, 2004). The discussions also gave me an opportunity to observe interactions between individuals and consider some of the ideas surrounding the social construction of meaning. The co-ordinator of the group acted as the facilitator and was well informed about my own aims as well as the sensitive nature of the discussion topic. These methods were triangulated by ‘participant observation’ both within the context of the Women’s Action Group and outside the group. Interviews were done where individuals felt most comfortable, in people’s houses or quiet public places or at the office where the women met for the group. The two FGD were convened at the meeting place in the house by the river, a venue known to most of the women and a place where they were comfortable. Having read the prepared information leaflet that I had composed, I discussed any questions with the women including restating the importance of confidentiality in the study. All names in the study are pseudonyms. I obtained written consent in all cases apart from one where verbal consent was sufficient. I covered any costs that were incurred by the women as a result of participating in the research. It was usually the cost of travel and something to eat. In order to improve the reliability of the data, I audio-taped the in-depth interviews and FGD. I jotted notes in a small note book after in-depth interviews and during observations as discretely as possible. These jottings were written up in a field work journal at the end of each day when I began to take note of the emerging themes. I observed and took notes during the FGD and similarly reflecting upon them and wrote about them in the journal at the end of the day.

Analysis & Writing up

All the in-depth interviews were fully transcribed. Relevant parts of the FGD were fully transcribed and main themes were written about the other parts.
Thematic content analysis was used to analyse the data categorising the common themes that were arising (Green & Thorogood, 2004). Each theme was coded, either with the emic term used or my own interpretive code. The codes were analysed in the context of my observations that I had written in the field work diary. In writing up this study I have aimed to stay close to the voices of the women and as such have included their words.

*Why I Didn’t Study Men*

Men appear to be silenced in this study partly because of the focus exclusively on motherhood. It was also partly a pragmatic choice since the limited time did not allow me to pursue their voices which I perceived would be more difficult to seek out as a woman researcher. I knew too that the women who were being diagnosed in the UK often discovered their status during routine antenatal testing, an activity that men simply do not engage in. I had wanted to study the experiences of the women partly because much of the critical medical anthropology that suited my ideals early in my studies had led me to consider African women as open to gender inequality that pervaded much of the structural level of their lives. I wondered what they would think about that perspective and particularly in their new context. Whilst their history resonates with these gender dimensions, as we have seen, they contest it as they acquire new knowledge. African and Zimbabwean men are not absent in the new context and they have not been entirely neglected in research. I imagine that there will be more activity in the light of a recent review that encouraged more attention to understanding the experiences of migrant heterosexual African men and African MSM living with HIV (Prost et al, 2007). In fact as I was preparing to leave for the field, my attention was drawn to a recently published article exploring the masculinities among heterosexual men living with HIV in London (Doyal et al, 2009). The researchers were surprised at the candour with which the men spoke about their experiences (Doyal et al, 2009). My own study would
be complemented by a gaze on the experiences of migrant Zimbabwean men living with HIV. I heard only whispers of their voices from the women and perceived that they may be more reluctant to speak. However, this may not be the case.
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ARVs</td>
<td>Anti Retro Viral</td>
</tr>
<tr>
<td>CD4</td>
<td>Cells destroyed by HIV, low CD4 count indicates damage to immunity</td>
</tr>
<tr>
<td>CIPU</td>
<td>Country and Information Policy Unit</td>
</tr>
<tr>
<td>COIs</td>
<td>Country of Origin Information Reports</td>
</tr>
<tr>
<td>GUM</td>
<td>Genito Urinary Medicine</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IVF</td>
<td>In Vitro Fertilisation</td>
</tr>
<tr>
<td>MDGs</td>
<td>Millennium Development Goals</td>
</tr>
<tr>
<td>MP</td>
<td>Minister of Parliament</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health System</td>
</tr>
<tr>
<td>PMCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>SRR</td>
<td>Sexual and Reproductive Rights</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>WOZA</td>
<td>Women of Zimbabwe Arise</td>
</tr>
</tbody>
</table>

### Transcript Conventions

- **wo-** Word interrupted by next utterance
- **(word)** Word(s) in round brackets indicate transcriber’s guess at unclear word.
- **CAPITALS** Words spoken more loudly than others
- **Emphasis** Words that are emphasised more than others
- **( . . . )** Unclear material omitted by transcriber
- **[ ]** Square brackets enclose material added by transcriber
- **. . .** Material omitted

(adapted from Green and Thorogood, 1994:101)
Bibliography

Aids Alliance
http://www.aidsalliance.org (29 April 09)

BBC News
2009 ‘Zimbabwe Police Still Harass Us’
http://news.bbc.co.uk/2/hi/africa/8107050.stm (20 June 09)

Bourdieu, P.

Bourdieu, P.

Bourdieu, P. & Wacquant, L.

Coker, R.
2004 Compulsory Screening of Immigrants for Tuberculosis and HIV
British Medical Journal 328(7437): 298-300

Csordas, T.

Danziger, R.

Doyal, L. & Anderson, J.

Doyal, L. & Anderson, J.
Doyal, L., Anderson, J. & Paparini, S.  

Farmer, P.  

Foucault, M.  

http://www.ukcoalition.org/migration/HIV-Treat_With_Respect1.pdf  (20 April 09)

Good, B. J.  

Green, J. & Thorogood, N.  

Hammers, F.F., Devaux, I., Alix, J. & Nardone, A  

Hardon, A., Boonmongkon, P, & Streefland, P. et al  

Iliffe, J.  
IPPF

Kesby, M. Fenton, K. Boyle, P. & Power, R.

Landzelius, K.

Lawless, S., Kippax, S. & Crawford, J.

Liamputtong, P.

Martin, E.
1994 Flexible Bodies: Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS. Boston: Beacon

Mathews, H. F.

Ndirangu, E, W. & Evans, C.

Nguyen, V-K.

Rose, N. & Novas, C.

Scheper-Hughes, N.

Scheper-Hughes, N. & Lock, M, M.

Schoepf, B, G.

Shilling, C.

Soomre, E.

Turner, T.
UNAIDS
2008   Aids Epidemic Update 2007 SSA Regional Summary
   http://www.unaids.org/en/KnowledgeCentre/HIVData/EpiUpdate/
   Archive/2007/default.asp   (20 April 09)

Welbourn, A.
2008   HIV/Aids: a War on Women. Open Democracy on line
   http://www.opendemocracy.net/article/5050/international_womens_ 
   day/hiv_aids#comments_for_node   (20 April 09)