

'A raw experience': a study of Nigerian women living with HIV in Jos, Nigeria

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Thesis submitted for the degree of Doctor of Philosophy (PhD)

2022

Declaration

I, Sophia Mark confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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List of abbreviations

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral therapy
HAART:	Highly Active Antiretroviral Treatment
HIV:	Human Immunodeficiency Virus
PEPFAR:	The U.S. President's Emergency Plan for AIDS Relief
PLWH:	People Living with HIV
PLWHA:	People Living with HIV/AIDS
NACA:	National Agency for the Control of AIDS
UNAIDS:	Joint United Nations Programme on HIV/AIDS
WLWH:	Women Living with HIV

Research Impact

Women living with HIV are an under-represented group in research even though they make up more than half of all people living with HIV worldwide. The findings of this research are specific to the experiences of Nigerian women living with HIV and provide important insights into their experiences. The findings from this research have an impact with both within and outside academia, the latter with regards to service delivery for women living with HIV in a non-western context.

With reference to academia, in recognising the impact of the HIV/AIDS epidemic on women, this study has contributed knowledge to fill the gaps in the literature on African women living with HIV in a country in the global South. This research study was an opportunity for female participants living with HIV to discuss about HIV and how they come to terms in living with a biographically altered self and for most of them, it is a gendered experience. For the treatment providers, this research has provided important insights for treatment providers and policymakers to consider when making decisions on policies that affect women living with HIV. This research explored the challenges faced by Nigerian women living with HIV and the findings of this study could lay the foundations for the development of a holistic, gender specific and culturally sensitive approach for counselling HIV positive women in Nigeria.

Abstract

Background

The aim of this study was to gain a better understanding of the experiences of HIV positive Nigerian women living in Jos, North-Central Nigeria. The study applied a feminist lens to illuminate their experiences, with reference to biographical disruption. Nigeria is estimated to have the second largest number of people living with HIV in the world and women are disproportionately affected and infected by HIV/AIDS yet little is known about women's experiences of living with HIV in Nigeria.

Methodology

The research used a qualitative approach, informed by Interpretative Phenomenological Analysis (IPA), to generate in-depth data from semi-structured interviews with 11 HIV positive women and each participant was interviewed three to four times. The study applied a feminist lens to IPA and also pays attention to the broader contextual issues that participants face as part of their experiences of living with HIV.

Findings

The analysis of the interview data identified three key themes: 1) Testing positive; 2) Living with HIV and 3) Disrupted Lives, 'Repaired Biographies'. These three overarching themes encompassed subthemes which provided in-depth information of individual participants' experiences.

Conclusion

The findings of this study provides useful knowledge on Nigerian women living with HIV. It provides insights for treatment providers and policymakers in Nigeria and further afield by better informing their services to women, particularly through scaling up counselling services that are gender-specific, gender-sensitive and the provision of additional support and specially trained professionals. This study also highlights the value of the IPA approach and the use of biographical disruption as an approach to explore the impact of HIV on women's lives. In addition to this, the study also highlights the need to pay attention to the wider contextual factors that impacts women living with HIV.

Acknowledgments and dedication

I would like to thank the eleven female participants who contributed so generously to this research through making time for interviews and the three service providers (clinics) who generously granted access to their counsellors and the eleven participants who were their clients at the time of this study; without their participation, this research study would not have been possible. The time I spent on fieldwork in Nigeria was a life-changing experience and I thank all who participated with me in this incredibly unique experience.

I am very grateful to Dr Aladi Agaba for the support she gave me during my fieldwork in Nigeria and long afterwards. I would like to thank my supervisors, Dr Ian Warwick and Dr Ruth Stewart for their valuable work in helping me through our numerous supervisory meetings and guidance, particularly in the process of writing up my research study. I would also like to acknowledge the support of Professor Michael O'Rourke, my former lecturer at Trinity College Dublin, who encouraged me to consider studying for a doctoral degree.

I am grateful to my family most specially my son, Noah. I am exceptionally grateful to my parents, the distinguished Senator David and Mrs Helen Mark and to all my brothers and sisters. In particular, words cannot express my gratitude to my parents for their support, encouragement and belief in me; they have both supported me and continued to believe in me even when I thought the possible impossible. I would also like to thank my husband Nick for his patience over the years. I love you all and can stand strong today because of your love and your belief in me. I am also grateful to my mentor, Ambassador Jane Ndem for her unwavering encouragement and support over the years. To all my friends in Jos, I thank you for all the support and help you gave throughout my fieldwork and thereafter, encouraging me, welcoming me to your homes and keeping me safe and sound, most especially Ochapa and Samson (those drinks- Amstel Malt in my case- and suya really helped). I would also like to thank the service treatment providers and all members of staff at these organisations who helped me to navigate the intricacies of the environment both within and outside the clinics. I particularly appreciate the kindness shown to me by members of staff at these clinics. There are many more names I would like to mention but space does not permit me to do so; suffice to say, I am extremely grateful to all who worked with me in one capacity or another during my studies.

Above all, I dedicate this work to the eleven women who gave their time in participating in this research study. Their strength, resilience and determination to overcome all odds touched and inspired me to complete this research. They have taught me that with God, everything is possible.

Introduction

In carrying this doctoral research, I am interested in understanding how HIV positive Nigerian women make sense of and experience life with HIV. In Ireland where I lived for many years and in the United Kingdom where I presently call home, I have seen how HIV has been redefined as a chronic, 'normal' illness but in Nigeria, I know people who have been diagnosed with HIV and died of AIDS and also people still dying from AIDS, even as recently as 2020, despite the availability of an effective treatment regime. Nigeria is in the midst of an AIDS epidemic and women are among those who have been infected and affected by the epidemic. Women play a key role in social reproduction in Nigerian society and are particularly vulnerable to HIV infection yet we still know so little about how HIV positive women live with it. For this reason, it is important to understand how Nigerian women live with HIV.

My first encounter with HIV came in the early 1990s when a woman came into my family home crying bitterly that she was sick and dying and had been abandoned by her husband and his family. Seeing this woman's pain was an unbearable experience for me. I witnessed the stigma and discrimination this woman experienced due to her HIV status. I have never forgotten her- I never saw her again and do not know what happened to her but I suspect that in the absence of treatment, she likely died afterwards, something that I understood was the reality for most Nigerians during the 1990s. My ancestral hometown of Otukpo has witnessed the devastating impact of the HIV/AIDS¹ epidemic with the loss of so many people in their prime; the epidemic has been experienced at all social strata including farmers, housewives, lawyers, doctors, accountants and teachers. Many children became orphans and some were themselves infected with HIV. Even my own family was not immune from this reality- I have lost several relatives to the disease and some of these relatives in turn left behind children to be cared for by other relatives.

¹ According to the United Kingdom's National Health Services (NHS), HIV and AIDS are distinct: HIV is a virus that damages the cells in the immune system and weakens the body's ability to fight infections and disease. AIDS is a term used to describe a number of potentially life-threatening infections and illnesses that occurs when the immune system has been damaged by the HIV virus. While AIDS cannot be transmitted from one person to another, the HIV virus can. With early diagnosis and treatment, most people with HIV won't develop any AIDS-related illnesses and can live a near-normal lifespan: <https://www.nhs.uk/conditions/hiv-and-aids/>

AIDS strained social and financial resources and stunted Otukpo's socio-economic progress, ramifications of which are still being felt, more than thirty years since my first encounter with an HIV positive woman. The epidemic also strained family relations- in my own extended family, a relative who was diagnosed with HIV in the 1990s was treated by other family members in the most horrific way possible- he was left alone in his own room as people began to avoid him, refused to enter his room and refused to share the same plate and cutlery with him. More than often not, family members left food for him by the door and expected him to feed himself even though he lacked the strength to do so due to severe illness. His HIV diagnosis marked a turning point in his life, something that I call 'biographical disruption', during which he experienced severe stigma and rejection from members of the family. It became a question of 'him' and the rest of 'us'- he was no longer considered a part of 'us'- he was now on his own, a pariah to the rest of the family.

Some relatives said that it was his own fault for contracting HIV and in a society where people share a strong collectivist outlook, ostracism is the equivalent of social death, a sense that one has died even when they still maintain a physical presence. Family members no longer saw him as a socially viable person and they deliberately cut him off from the family circle. Perhaps not surprisingly, he died less than a year later. Once buried, he became forgotten, another footnote in my hometown's AIDS statistics. In my culture, we celebrate the life of a person who passes on and there might be memorial activities such as thanksgivings in church to remember departed relatives but in this relative's case, his name is rarely mentioned these days. He left behind his fiancé who later passed on from AIDS. My interest however lies in understanding women's experiences of HIV, something that is a legacy of my interaction with the woman who came into my family home in the 1990s. She was a woman who struggled to find her voice, something that I later noticed was the same case for Nigerian women in general.

In positioning my own research as a research for and about women, I also wish to state the rationale being this- firstly, I acknowledge gender as a powerful social construction and that women and more specifically, Nigerian women live in a patriarchal society, which devalues them and their contribution and reduces them to being mothers, wives and carers. Secondly, Nigerian women are part of a group who

remain disproportionately disadvantaged by their status as black, African² and poor women. By this, I mean that black women have been invisible in research studies on HIV except when they are presented in HIV literature in terms of numbers and statistics. The majority of studies carried out on African women have focused on the experiences of black South African women, with the majority of these studies carried out by white South African researchers who do not necessarily share the same experiences with black women apart from their South African nationality. As a group, black African women are hit hardest by poverty, violent civil and political conflicts across much of the continent and lack of access to social, economic and political resources and adequate healthcare (Ramjee and Daniels 2013), which renders their voices unheard and limits knowledge about them.

For female researchers of black African origin like myself, even though my research is about women, I had questions about what feminism is; as a term, feminism is a difficult and complex topic that goes beyond notions of male/female issues which makes it much harder to define precisely what feminism is or is not. A Cameroonian feminist scholar once asked whether feminism exists in Africa and if so what form it takes. Atanga (2013) postulates that feminism does exist but the notion of what constitutes feminism, particularly with reference to African women, has been complicated by confusion about Africa itself. Should Africa be considered a geographical or cultural landscape? From my own standpoint, Africa is a diverse continent with different countries, cultures and religions and African women do not necessarily share the same experiences- Nigerian and Kenyan women have much in common in being black African women but do not speak the same language or share same histories, experiences or cultures. Likewise, the experiences of Zimbabwean or Nigerian women cannot be generalized to those of South African women. Neither can those of Afro-Brazilian women to Nigerian or Ghanaian women. Nevertheless, people of African descent share some common similarities that mark them out from other people from other countries and continents- for example, Nigerians and

² In using the term, 'African', I wish to acknowledge that 'Africa' is not a single heterogeneity but rather, a continent with multiple nations, cultures, religions, national origins and languages. I acknowledge this in my reference to the work of the Cameroonian feminist Lilian Lem Atanga. In this study, I make use of the, 'African' as a blanket term, with the understanding that African is not a homogenous entity.

Ghanaians having more in common with each other than with European or Asian cultures (Idang 2015).³

Due to the board range of philosophical and methodological approaches that encompasses feminism, in seeking to explore and understand the experiences of African women living with HIV, I have decided to concentrate on the experiences of women from one country, Nigeria. I describe Nigerian women as *black* women and *African* women. Hill Collins (2002:2) has argued ‘black feminist thought encompasses the theoretical interpretation of Black women’s reality by those who live and experience it.’ Nigerian women are black and African women who have both personal and special knowledge of their own reality of what it means to be black women and for those who are HIV positive, what it means to be black and African women living with HIV. As a group, black women have been subject to racism and sexism on a daily basis- racism and sexism tends to negatively reinforce each other, which means that for black women of African descent globally, being black and female is a double burden, particularly if they are living with marginalized identities (Spates et al 2019; Hogan et al 2018). Douglas (1992) argues that as a group, black women are under-represented in research studies. Even studies that include black women often reduce them to statistics. Current gaps in the literature suggests that there is an urgent need for studies that focuses on the lived experience of black women of African descent, within both Africa and the diaspora. Douglas (1992:43) recommends that such studies should involve black women ‘in setting the research agenda and conducting future research. Many academic organizations are structured in such a way that black women are excluded from the research process.’

HIV has had a disproportionate impact on people and in particular, women, of African descent across the world. When HIV was first identified, it took several years for this impact to be recognised and to be understood- the early focus was instead on white homosexual males in the United States and Europe. In particular, HIV has infected and affected women from sub-Saharan Africa including Nigeria, in disproportionate numbers compared to other parts of the world (UNAIDS 2021). HIV is not just a health issue but is one that has had profound social, cultural, economic

³ In this study, when the term ‘African’ is used, I do this with the understanding that although Africa is a continent with different cultures, religions, languages and ethnicities, Africans do share some commonalities- as Idang (2015:100) states, ‘there are sufficient similarities to justify our usage of the term “African culture”’

and political impacts. AIDS interrupts and disrupts lives in many ways that the literature have not always acknowledged. In carrying out this research study, I have put women at the centre stage. The participants are Nigerian women who were diagnosed with HIV after 1997 and they experienced a different kind of 'biographical disruption' from that of the woman who came to my family compound in the early 1990s because their diagnosis came at a critical point of the HIV epidemic. From the late 1990s onwards, the epidemic witnessed several turning points including a redefinition of HIV/AIDS due to improved treatment therapy and increased social and political activism, particularly in South Africa, where many PLWH (People living with HIV) actively campaigned to increase access to treatment for all PLWH, irrespective of gender, race, religion or ethnicity. Although HIV is no longer considered the death sentence it once was, living with HIV remains a complex experience with biomedical, social and psychological consequences for PLWH, particularly for women. In Nigeria, as this study will demonstrate, WLWH (Women living with HIV) inhabit complex spaces in which their lives are often unstable and unpredictable.

Chapter One introduces the researcher in the fieldwork, drawing elements from researcher's field notes and reflexive thinking. The field notes are quite raw and whilst contains some spelling and grammatical errors, this was not intentional because I wrote these notes in the context of my daily experiences during fieldwork where I kept a journal and often wrote quickly. From these notes, I was able to capture the gendered experiences of life in Nigeria and to refine and define the broader and specific aims of the research study. The field notes helped me to bring a feminist perspective to the entire research. Chapter two presents a review of the relevant literature. It begins by contextualizing feminism, patriarchy and HIV and introduces conceptions of gender, chronic illness and biographical disruption. The chapter continues with a review of the literature on biographical disruption and the ways that it has been applied, adapted and explored in research studies. Chapter three presents the philosophical assumptions and introduces a feminist lens to the research methodology – IPA. Chapter four discusses the research methods, participants and the ways I carried out the research. Chapters five, six and seven focus on the findings drawn out from the interview data and chapter eight discusses the findings of the study, areas of future research and recommendations for treatment organisations in helping women come to terms with HIV.

Chapter One

*Yes my little child, I have many stories to tell
you, stories of my life,
our life, and the lives of all women around the world. They are tales I
have known forever; they are as much a part of me as my skin. I can
feel them even now, as I watch the clock of life tick by. I have seen a
great deal of this life. The tale can be told, retold. This is a sad story,
from a sad place*

Mace Mutum by Rahma Abdul Majid

Introduction

In this chapter, I present some of the notes that I wrote during fieldwork. These notes were written over the course of a year and half and I wanted to include these notes in the thesis as they were quite useful in helping me frame my research in terms that are more definitive. The initial aim of the study had been to study the work of counsellors working with HIV positive women and I have received training as an HIV counselling and testing counsellor myself but as I began fieldwork, it became clearer to me that my focus had to shift- it is essential to understand how HIV positive Nigerian women live with a chronic condition- this shift came about because of the trend towards biomedicalising HIV in treatment providers. As a result improved treatment, HIV was no longer just a social problem but one that could be treated with medical intervention and therefore, the attention of policymakers has shifted towards addressing HIV through medical intervention. I found that this shift did not fully address issues that are specific to women and has left them at a distinct disadvantage. To this end, my fieldwork started with participating in counselling sessions and conversations with counsellors and then to HIV positive women themselves who have been living with HIV for many years- the conversations that I had with women living with HIV would later form the basis of this doctoral thesis. The notes and observations made during fieldwork helped me to draw out my research aim and questions clearly, to apply a feminist lens as well as positioning my

research. The end result is a research study that is quite rich in the data presented and discussed in later chapters of this doctoral research.

1.1 The researcher in the field: excerpts from field notes

1.1.1 Field notes, 31st January 2013

The fourth counselling session this morning involved a married couple and was in the Hausa language. It was a long, difficult and deeply distressing counselling session. The wife was pregnant and like her husband, was in shock- she had gone for antenatal treatment elsewhere last week and the clinician there tested her blood sample without her knowledge nor consent and then told her that she is HIV positive. The clinician wrote a referral for her to go to an HIV treatment provider. Thus, the first question that Ella had asked the couple was whether they knew that this clinic was for and what they were at the clinic for and they replied in the affirmative. The counsellor asked them about their testing history. The couple had taken an HIV test as advised by their Church pastor prior to their marriage about six months ago and had both tested negative. They began trying for a child immediately after their wedding. The couple are struggling to understand how they could both test negative just six months ago only for her to be positive now that she was already pregnant- they had enrolled for an antenatal programme at a clinic that ran an HIV test without the couple's knowledge nor consent. They asked Ella whether their first tests not been done correctly six months ago? Ella explained that she couldn't possibly comment about their last test as she didn't know what had transpired during their last session and it been done elsewhere but she explained about the window period and the need to go back to retest again. Apparently, the couple had not re-tested and it is not clear whether or not their previous counsellor told them about the window period but the couple claimed they were never informed of this. Throughout the counselling session, Ella had to cajole the husband to respond to questions. Ella gave them information about HIV and the testing procedure. She asked them what they would do if they got a positive test result. The wife asked her husband whether he would still love her if her test confirms that she is HIV positive but he failed to respond. Ella took their blood which she sent off to the lab; the couple were advised to come back later in the afternoon to collect their results.

Later that afternoon, the couple arrived at Ella's office to collect their results. The wife was visibly distressed and she began weeping after Ella confirmed that she had tested positive but her husband's test result is negative. Her husband was too shocked to speak. There was not much Ella could do other than let the couple absorb the news and empathise with them about their situation. After some minutes, Ella spoke again; it was clear that the couple were not really listening to her and the woman was still in tears- they were simply too shocked and distressed by the life changing news that they had just received. The counsellor advised them to go back home and talk and for the wife to come back the next morning to start treatment so that she could reduce the risks of transmitting HIV to her baby. The couple left the counselling unit with a pack of condoms. Ella herself was sad as she admitted after the couple left that she hates having to tell pregnant women that they are positive-

she herself is a mother and understands how hard it is for pregnant women to receive such distressing news. Ella felt that she had no choice but to distance herself from her emotions and carry on talking but she knew that the woman was inconsolable and was not really listening to her words at that point. What more could she do other than to refer the woman to another part of the clinic to begin her treatment?

1.1.2 Field notes, 1st February 2013

The following day, I saw this woman at the main treatment unit waiting to be called to start treatment. She was there without her husband and was still crying. She was being supported by a female support worker who expressed concerns for the woman's emotional state due to her advanced stage of pregnancy. She was now having to start the treatment process to prevent mother to child transmission of HIV and she was being reassured by her support worker that with treatment, she would likely not pass the virus to her baby and she herself could live positively and normally so that that she could take careful of herself and her baby. However, for this woman, it was clear that a lot more was at stake than just her HIV diagnosis, something that even the counsellors themselves understood. The clue was in the rather striking question she had asked her husband during the pre-testing counselling session the previous day- she had asked him whether he would still love her if she were to test positive for HIV and he had not responded. Now that she is positive, her husband's response remained silent. His silent response would shape both hers, his and society's response to her HIV status. HIV had an enormous impact on the woman's identity as a wife, a mother and valued member of her social world. How would people view her now that she is HIV positive? How would she be able to live with a condition that is widely misunderstood, denied, stigmatized and dreaded? What would happen to her marriage? Would her husband continue to love her or would he ask her to leave?

1.1.2.1 Reflexive notes

The counselling sessions and interactions so far have made me to reflect on my own values, beliefs, gender and class- have these influenced the ways in which I approach my research? This pregnant woman's experience today reminded me of how different my life and my values are from her situated reality as she experienced it. I lived in Nigeria until I was ten years old. My father is a retired army officer whose job took him all over Nigeria and my mother was a nutritionist who rose to become head of catering in a polytechnic and then was later elected my hometown's first female mayor. Due to the nature of my father's job and the need for stability, I lived with my mother in Kaduna, Northern Nigeria in an accommodation provided by her employer. This accommodation was in a small middle class enclave that was surrounded by a large and busy market and working class settlement that experienced high crime rates and frequent religious clashes between Muslims and Christians. I was exposed to extreme poverty even though I didn't experience it directly and in the primary school that I attended, I saw the gender biases that girls were subjected- I was one of only a handful of girls in my class, as parents withdrew their daughters from school for marriage- my best friend who lived near me and who

attended the same school was withdrawn from school for marriage when she was only 13- we were in the same class but she was older, as she started school much later than I did and once she got married, our friendship came to an end. In reflecting back on gender biases and the counselling session involving this woman, I became curious about hearing the voices of women who have tested positive for HIV. I have become aware through my observations in the field that women's experiences of living with HIV and the challenges that they face are not always understood nor recognised by service providers. This woman had asked her husband whether he would still love her if she tests positive but he had not responded- to me, this was a striking question and the counsellor did not provide any advice other than to give the couple a pack of condoms and left them to work things out themselves (although I understand that it is not Ella's position to counsel the couple beyond HIV testing). It was clear that for this woman, life is going to be challenging and hard and her life would be shaped by factors beyond her control- her experience has led me to consider exploring further the broader contexts in which women experience life with HIV in my research.

1.1.3 Field notes, 3rd February 2013: Informal conversations with counsellors

Just last week, I had some informal conversations with several members of the pre-treatment counselling team and these discussions touched on the issues relating to gender and HIV. The head counsellor pointed out that the majority of patients waiting to start treatment or receive treatment in the clinic were women (although the majority of doctors were male): 'you see, Sophie, most of our patients are women and many of them come from outside this town.' From these conversations, it was clear that the main reason for the stigma against HIV has to do with widespread perception of HIV as a sexually transmitted disease. Sex is very much a part of the human psyche but talking about sex is an embarrassing topic among Nigerians. Christians and Muslims have much in common in viewing sex as something that should not be discussed so openly and as something that should only occur within marriage between a man and woman. The counsellors noted that women have been marginalized and oppressed by Nigerian society which has therefore stripped them of their voices. One female counsellor opined that by rendering women voiceless, society has left them unable to take measures such as safe sex to protect themselves from HIV and other sexually transmitted infections.

The counsellors pointed out that Nigerian women rarely divorce unfaithful spouses and women have been accused of spreading HIV. The counsellor used her own example- she is very much aware of her husband's extra-marital activities yet rather than questioning him, she admits to taking her own steps to protect herself by taking HIV tests on a regular basis. Counsellors told me that Nigerian women rarely refuse sex with their husbands even if it leaves them at risk of contracting sexually transmitted diseases. To further underline the oppression faced by Nigerian women, one counsellor [Ana] told me that some Nigerian languages lack proper gender pronouns for words such as 'he', 'she' because these words mean the same thing. Personal description of gender terms are directly translated as 'the man' or 'the woman' but never 'he', 'she', 'him' or 'her'- an anomaly that renders women voiceless by highlighting their invisibility and therefore, their weakness. To this counsellor, the lack of personal gender pronouns in Nigerian languages seems to suggest lack of

identity and voice for women. Without 'proper pronouns', how does she address her female clients? How can she validate her clients as individual women in their own right? This counsellor told me that words and language can define social experience by describing people and how they connect with the world around them as well as with their selves.

1.1.3.1 Reflexive notes

I am curious about what the experience of living with HIV is like for women who have been living with it since their diagnosis and from the many conversations that I have had with counsellors, it makes sense to focus on women who have been living with it for at least a year. Gender is part of the bigger picture of HIV in Nigeria. I want to know whether culture, gender and class plays a role in women's experiences. I want to know about their fears and their relationships with their wider world and as I reflect on myself in the field, I am aware myself that gender and power dynamics both influence the way that I approach my research, particularly in terms of my relationship with women- I come from an upper class section of society and my values and experiences as a woman are vastly different from those of the other women that I have encountered in the field. I have had access to a career, education and power that the women I have encountered in the field do not have and I am aware that I am carrying out my research in a low income country. I understand from the discussions with counsellors that I have to take a sensitive approach to all aspects of my research, particularly as HIV is a highly stigmatised condition in Nigeria and I do not share the same health condition as these women.

1.1.4 Field notes, 15th May, 2013

New changes had been implemented in the HCT counselling unit with regards to the counselling process in the weeks since I had last seen Ella. Previously, clients who took their HIV tests had to come back to collect their results but the time lag between testing and collection of results meant that the counselling process was longer than it should be and many clients never came back to collect their results. To overcome this, the organisation decided to implement new changes using Rapid Testing kits, which can provide results for HIV tests in minutes rather than hours or days. Ella preferred this, as it meant she could see clients and give them their HIV results right away, which reduced her workload and stress levels. Ella's organisation has placed emphasis on condom use as a way of reducing the spread of HIV but the two other treatment providers I was working with as part of my research took a different approach. One of these organisations talks about condom but insists that it is not 100% reliable while the other warns about the dangers of pre-marital and extra-marital sex and insists on sex with marriage between a husband and wife only. It does not approve of sexual relations between unmarried couples. It was clear that not all unmarried Christians heeded this approach.

A young woman came in for an HIV test this afternoon. She is currently in a relationship with a fellow church member who has been refusing to use condoms during sex. The woman told Ella that her boyfriend 'knows himself' - meaning that he does not have a sexually transmitted infection and he was very sure of not having

HIV. The young woman insisted that she has herself too does not have HIV but she was checking herself out all the same because she had been having unprotected sex. Ella asked her why her boyfriend had not come with her and she admitted that she didn't expect her boyfriend to test himself since he was so sure of his status. The woman made it clear to Ella that she was not expecting a positive test result even though Ella tried to warn her to consider this possibility. Unfortunately, her test returned a positive result, confirming that she is HIV positive. When Ella asked her how she was feeling about her HIV test result, she remained silent but it was clear that the test result had shaken her and she was too shocked. She was no longer even looking at Ella. The woman left Ella's office still shocked.

Not long afterwards, Ella asked me how my research with the participants was going. Like the other counsellors, she was curious as to why I had chosen to focus my research solely on women and I explained that it was because women bear the greatest burden of living with HIV/AIDS yet there are very few studies on Nigerian women living with HIV. I spoke of the importance of focusing on women because of the need to know and to understand how Nigerian women live with HIV. A great deal of emphasis is on those newly diagnosed with HIV but what about those women who are already living with HIV once they have started treatment? It is known that issues such as poverty, lack of education and gender inequality are key factors in driving the HIV/AIDS epidemic and these same issues came across during counselling sessions but what happens once these women test positive for HIV, start receiving treatment and living with HIV?

1.1.4.1 Reflexive note

This counselling session reminded me that young women are at huge risks of HIV and many of them lack the power to negotiate safe sex. The conversation that I had with Ella after this session reminded me of what Ria say during a meeting that took place at treatment provider B on 5th April. The head of the organisation insisted that the monthly support group meeting needed to hold on Saturdays rather than during a weekday- Ria tried to explain that this would be difficult for some people, as they usually had other things to do on Saturday. A weekday was the only time of the week that people are likely to attend- her words were 'big people don't attend support group meetings, it is only poor ones like me.' These words struck me- 'big people' and 'poor ones like me' reveals that she understands that she is part of a society which is divided unequally between the rich and poor and she feels this inequality through her daily struggles for money. The words are sad for me because of the way she spoke and the harsh realities she faces every day. When Ria mentioned 'poor people like me', the head countered that, 'well, you are working'- suggesting that because she was receiving a salary, she is not poor. I could see where the head was coming from with regards to the timing of the support group meeting but his argument that Ria is working also struck a painful chord for me- it revealed the power inequality that exists between men and women- men don't always realise nor understand the power they hold over women and they don't always realize the hardships women like Ria face every day. The head's attitude appeared dismissive, although it was probably not intentional but Ria nonetheless accepted his decision.

Nobody stood up to support Ria when she offered her reasons for holding a support group meeting on a weekday. Ria was silent not just by the head but also by her colleagues. The same way that Ria was silent by male assertiveness is the same way the young woman Ella tested today was also silent by her partner's claim to know his HIV status yet he infected her.

1.2 Positioning my research

At the onset of fieldwork, as a researcher who has herself also received training in HIV testing and counselling, I was interested in exploring the work of counsellors. During fieldwork however, I made a number of observations including the emphasis by treatment providers on treating the medical aspect of HIV. The treatment providers in this study have coined the phrase, 'Living Positively' with HIV to encourage their clients to take steps to live with HIV yet it became clear that they had little understanding of how women who are diagnosed with and having been living with HIV make sense of living with it. Instead, their focus was on the bio-medicalisation of HIV, with its attendant processes of testing patients for HIV and the treating them with ARTs if they test positive. This biomedical trajectory has been expanded to using HIV treatments as prevention. As part of the focus on biomedicalising HIV/AIDS, treatment organisations have emphasised on the need for their patients to take their ARV medications on a regular basis, eat healthy nutritious foods, have access to clean water and take preventative steps to protect their health such as using mosquito nests to prevent malaria, not consuming uncooked foods or meats or reducing their sugar consumption and so forth. The push towards bio-medicalisation, which organisations have termed as 'Living Positively', however means that there has been little attention given to the socio-cultural factors that contributes to the spread of HIV in Nigeria and in particular for people who subsequently start treatment after testing positive, little is known about how they make sense of living with HIV in the context of biographical disruption, stigma, poverty and discrimination.

1.2.1 Women, HIV and 'Living Positively'

As I noted from observations in the field and from discussions with counsellors and the female participants themselves, women remain the group most severely and

disproportionately affected by HIV and much of the epidemic has been driven by gender inequality. Gender inequality has a negative impact on all aspects of society, economic activities, health and well-being. Discrimination against women in Nigeria remains pervasive with destructive effects such as higher levels of illiteracy, high infant mortality, lower political representation at local, state and national levels and violence against girls and women.

It has long been recognised that gender inequality plays a major role in increasing women's vulnerability to HIV/AIDS. Gender inequality contributes to what Wathula (2016) has theorised as 'feminisation of poverty'; Wathula (2016) argues that gender inequality has rendered women particularly vulnerable to HIV in a patriarchal culture where men are seen as superior to women. Both from my own observation and conversations with counsellors, the majority of clients receiving treatment at service providers are women who have come from all over Nigeria. These women share much in common in being individuals who have been circumscribed by socio-cultural notions of gender rights and are expected to accept these cultural customs. In most Nigerian cultural traditions, women are widely considered to be mothers, wives, carers and daughters who take care of others, yet are unable to protect themselves from HIV, constrained by both social and cultural factors. Women are also less likely to be educated, less likely to have access social, cultural and political powers than men and are more likely to live in poverty. In Nigeria, HIV is said to have a 'female face' (Anugwom and Anugwom 2016).

It is also women who carry some of the biggest burdens of living with HIV/AIDS yet in the service providers involved in this study, their voices were largely silent. Treatment organisations used the term, 'Living Positively' to describe how people can live positively with HIV by taking their ARVs as prescribed, having a balanced and nutritious diet, access to clean water and taking preventative steps to maintain their health, such as using mosquito nets to prevent malaria or avoid drinking unpasteurised dairy products. Women are seen at treatment organisations as clients who can be treated for what has now been termed a 'chronic illness'. The majority of people coming to test to know their HIV status and to receive treatment are women; the majority of counsellors, nurses and middle ranking administrators at these service providers are women yet rarely are women seen as unique experts who can

tell others what it means to be HIV positive and what it means to live with it. It is in response to this gap in the knowledge and understanding of the experiences of Nigerian women living with HIV that I have undertaken this study.

This dissertation builds on more than two years of qualitative fieldwork with a group of HIV positive women living in the city of Jos, North-Central Nigeria. By adopting a phenomenological approach with hermeneutic lenses, the aim of this research was to create a space where Nigerian women can speak about their experiences of living with HIV with their own authentic voice. This research study is qualitative in nature, with open-ended questions to give priority to the stories the participants tell of their experience of living with HIV. The theoretical framework of this research was framed by the notion of the diagnosis of chronic illness as biographic disruption (Bury 1982) and the experience of living with HIV was also framed within a feminist perspective.

In exploring Nigerian women's experience of living with HIV, this research began with exploratory fieldwork notes in suggesting that the gender inequality that frames Nigerian society has increased women's vulnerability to HIV/AIDS infection. This inequality also makes it difficult for women to negotiate life with HIV. In Nigeria, social, economic and political power largely lies in the hands of men (Omodia et al 2013). This suggestion is nothing new and has been the subject of several other studies across the world. For example, separate studies from Kenya and South Africa suggest that women are often unable to negotiate agency in their intimate relationships and they often lack the ability to control their bodies, as these are often seen as the commodities of their fathers if single or husbands, if married (Madiba & Ngwenya 2017). As another example, Northern Nigeria, despite its varying cultural, social and religious traditions, is a highly gendered society where women as a group lack opportunities to participate actively in social, economic and political life on the same level as men. Culture and religion both have strong impacts on women's access to education- for example, early withdrawal of young girls from formal education for the purpose of child marriage, a widespread phenomenon in Muslim Northern Nigerian communities- in fact, Nigeria has one of the highest rates of early marriages in the world (Mobolaji et al 2020). There is also a tendency towards early motherhood among girls and women in Northern Nigeria, which has had a devastating impact on these young girls, something that I personally witnessed from

seeing large numbers of young girls receiving for vesicovaginal fistula (VVF) at one of the organisations that participated in the study.

Men often make decisions about sex, condom use and sexual reproduction (Ramjee & Daniels 2013). In confronting similar realities in this research study of Nigerian women living with HIV, it becomes clear that living with HIV/AIDS is a far more complex issue that goes beyond the notion of 'Living Positively' with HIV that the organisations in this research have adopted, as I had observed during fieldwork. As can be seen from the accounts presented here from field notes so far, the experience of living with HIV is one that brings enormous upheaval for the individual concerned. It disrupts life, plans and brings an element of uncertainty which results in what Bury (1982) has termed as 'biographical disruption'. With HIV, women's emotional security is also at risk. They must find answers to questions about why and how they contracted HIV, how to be able to function in a world of uncertainty and how to negotiate meaning with HIV. They must learn to live with a new 'normal' where they face stigma, discrimination and are devalued as women and individuals because of their HIV status.

1.3 Aim of the study and research questions

I want to explore the lived experience of Nigerian women living with HIV with particular reference to Bury (1982)'s notion of chronic illness as biographical disruption. In carrying out this research, I aim to apply a feminist lens to explore the experience of HIV for a group of Nigerian women living in Jos, North-Central Nigeria and I pay some attention to context-driven intersectional factors such as gender, power and poverty. I wanted to explore their lives in the context of an illness that has disrupted their lives and wider social relationships.

The aim of this research study is to generate new knowledge about the experiences of women living with HIV in Jos, Nigeria, focusing particularly on their experiences, perceptions and contexts and to identify implications for theory and practice. To this end, my research asks the following questions:

1. Drawing on existing literature, what key themes have been reported about the experiences of women living with HIV in Nigeria and how do these themes resonate with ideas related to biographical disruption and issues of gender relations and power?
2. Through fieldwork with women in Nigeria, what are the participants' own experiences of HIV and the ways in which these experiences have been shaped by gender related power and do ideas about biographical disruption inform their experiences?
3. Through a discussion of the findings, what are the commonalities and differences between the themes identified in the literature and the accounts of the research participants themselves? What are the implications for theory and practice?

The scope of the study was confined to geographical, content and time scope within the study sites. Geographically, the scope of the study was limited to three treatment providers in Jos, North-Central Nigeria from which all participants were recruited. The study explored the experience of a group of women living with HIV and the study took place over more than a year, including a combination fieldwork observation and interviews with participants and counsellors.

1.4 Significance of the study

This research has the potential to provide insights and understandings of the experiences of living with HIV for a group of Nigerian women, given the paucity of research in this area of study. Most studies on women living with HIV have concentrated largely on women living in countries in the global North. There have been studies on African women in countries such as Malawi, Botswana, South Africa and Zimbabwe but there are limited research studies focusing on the experience of Nigerian women living with HIV. There is a gap in our knowledge and understanding of Nigerian women's experience of life with HIV. This study thus has the potential to generate new knowledge and understandings of Nigerian women and to contribute to the literature on HIV positive women.

Chapter Two: a literature review

Introduction

In this chapter, I discuss the existing literature that is relevant to the topic of women with HIV and biographical disruption. The literature review has been divided into two parts- in the first section, I provide some statistical information on HIV/AIDS. This is followed by a review of the literature on Nigerian women. This section engages in a discussion of the gendered aspects of HIV and notions of patriarchy and feminism, noting that with reference to HIV positive Nigerian women, there is a need to apply a feminist lens to study their experience of living with HIV. The next section then introduces the theoretical framework of this doctoral thesis, notably Bury (1982)'s notion of chronic illness as biographical disruption. This section also provides a review of the literature on gender, chronic illness and HIV. The chapter concludes with a justification for adopting biographical disruption in framing the emerging study.

2.1 HIV/AIDS: the global, regional picture and local picture

HIV/AIDS is a major global public health issue; since its emergence in the 1980s, an estimated 25 million people worldwide have died from AIDS. Globally, an estimated 37.7 million people are living with HIV and Sub-Saharan Africa is the most affected region, being home to an estimated 25.3 million PLWH (UNAIDS 2020). Globally too, 66% of all new adult infections are in Sub-Saharan Africa. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), an estimated 1.4% of Nigerians aged between 15 and 49 are infected with HIV, the virus that causes AIDS (UNAIDS 2019). This translates to a figure of approximately 3.2 million people, 1.9 million of them women in the cited age group (UNAIDS 2019). Globally, Nigeria has the second highest number of people living with HIV/AIDS (PLWHA) after South Africa (Awofala and Ogundele 2018).

In Nigeria, women have the fastest growing prevalence rate (NACA 2016) and AIDS remains a major cause of death in Nigeria (NACA 2014). According to estimates, 59.37 per cent of Nigerians living with HIV/AIDS are girls and women (UNAIDS

2018). Not only are women more likely to be infected with HIV, they are also more likely to care for others living with HIV and they bear many extra burdens such as childcare and housework, often on their own (Asuquo et al 2017). Although Nigeria has the second largest number of PLWH and women constitute a large proportion of this figure, women's voices are largely absent from the literature on HIV in Nigeria. These statistics demonstrates that the experiences of Nigeria women living with HIV are worth further study, and in particular, there is a need for an in-depth qualitative research study which aims to make sense of how Nigerian women live with HIV.

2.2 Missing Voices: Nigerian women living with HIV

Nigerian women have been actively engaged in local initiatives to address the HIV/AIDS epidemic since the early years of the epidemic yet their efforts have not been widely recognised in the literature on HIV/AIDS. This situation is similar to that experienced in the United States in the late 1980s and early 1990s, where Corea (1992) wrote one of the earliest accounts of women and the HIV/AIDS epidemic; she noted that women's voices were initially absent from early accounts of the emerging epidemic. As the focus was on the four H's- homosexuals, heroin drug users, Haitians and haemophiliacs, women's accounts and their symptoms simply didn't fit into the restrictive narratives of HIV/AIDS at the time. Corea (1992) acknowledges that whilst it is true that narratives of early stages of new diseases are usually restrictive due to a lack of knowledge or understanding, she argued that epidemiologists and other medical experts were unwilling to recognise that women too were also victims of the disease and that during the early years of the epidemic, women with HIV were seen as 'the other'- sex workers, drug users and ethnic minority women and as such, their accounts were considered irrelevant, leading to delays in research on women with HIV and stigmatization of HIV positive women.

Durvasula (2018) states that in the early years, 'as HIV became a 'morality tale' for women, the conversations about HIV in women were silenced and shamed- delaying testing and treatment for all women. The politics of HIV were played out vociferously in gay men and culminated in some of the most powerful political movements in public health of the 21st century. Political delays negatively impacted both men and women, but these delays were augmented for women because the very women who

were most impacted were least likely to have a voice.’ The first case of HIV/AIDS was in Nigeria was identified in 13-year-old female but HIV/AIDS was met with widespread scepticism and denial and there was little official efforts to tackle the growing epidemic (Awofala and Ogundele 2018). Evidence from the 2000s pointed to a growing feminization of the epidemic and among the factors cited for the gender disparity were poverty, child marriage, gender-based violence and harmful cultural traditions (Ibid). Little attention was paid at the time to Nigerian women living with HIV yet it was difficult to ignore the gendered aspects of HIV/AIDS in Nigeria.

In the early 2000s when I began to engage with literature on HIV, I struggled to find articles or books relating to women and more specifically to Nigerian women living with HIV. Early articles written on black African women in the early years of the epidemic did not do justice to African women because they often referred to Africa as a single entity, ignoring it as a continent with over fifty nations, different histories, cultures and traditions and in particular, West Africa, where Nigeria is located, was ignored. Much of the available literature including Randy Shilts’ classic work, *And the Band Played on*, also focused on the experiences of gay men, which whilst engaging and interesting, did not provide information about women’s experience of HIV. Then in 2004, I came across a newspaper article that appeared in the New York Times: **‘A name, not a number: Yinka Jegede-Ekpe admitted she had AIDS despite the prejudice it would cause, but now her story has become a beacon of hope** written by John Donnelly. This article was a revelation for me, as it was the first article that I have ever read about an HIV positive Nigerian woman.

Today, HIV is a chronic⁴ and treatable condition, but back in 2004, it was a dreaded and highly stigmatized disease in Nigeria and there was little or no clear distinction between HIV and AIDS. At the time, HIV/AIDS was seen in terms of statistics and figures and pain, suffering and death but the title of the article on Jegede-Ekpe sought to see her experience not in terms of numbers but as an individual with a narrative of living with HIV. Jegede-Ekpe’s story further reignited my interest in exploring the lives of HIV positive Nigerian women. This newspaper article presented

⁴ In this study, I will mainly be referring to HIV as a chronic illness rather than a disease. Boyd (2000:10-11) suggests that there are key differences between terms such as ‘illness’ and ‘disease’ - disease suggests that something is pathological but ‘illness’ can be viewed as ‘a feeling, an experience of unhealthy which is entirely personal, interior to the person of the patient.... Illness is the patient’s experience of ill health.’ <http://mh.bmj.com/content/medhum/26/1/9.full.pdf>

Jegede-Ekpe's account in quite biographic terms that changed my understanding of HIV; until then, I had not understood HIV as a chronic illness but rather, as one that could lead to death. Donnelly (2004)'s article stood out for me because the central character was Nigerian and most importantly, the character was a woman.

In describing her own work as an HIV activist, Jegede-Ekpe's gender has been a key feature of living with HIV, something she has herself stressed in a video interview on her work: 'Every time maybe we're having a support group meeting, men do the talking, while women do the looking and listening. I felt no. This is not right. Women are worst hit by the epidemic and they're so quiet? I said this is not ok.'⁵ The HIV/AIDS landscape in Nigeria has been shaped by gendered experiences since the beginning of the epidemic there. The gendered experiences that Jegede-Ekpe noted was something that I also observed when I was in Nigeria and was brought into further sharp relief during fieldwork.

Women dominated both the clinical and non-clinical landscapes in my study- the majority of people coming to take HIV tests are women, the majority of people receiving HIV treatment are women and the majority of staff are women. However, men were at the apex of decision-making about policies and processes within both clinical and non-clinical settings that largely affected women. These gendered experiences reminded me that at its core, Nigeria remains a patriarchal society. In anthropological terms, 'patriarchy' refers to an arrangement in which men dominate over women by holding more social, political and economic power- in a patriarchal society, men disproportionately hold power and women are often either excluded or marginalised (Walby 1990). Walby (1990) suggests that patriarchy can also be seen in the structuring of society through the family unit where fathers have the primary responsibility for and authority over their families. In short, patriarchy is a celebration of male dominance over women. In Nigeria, social acceptance of women come through marriage (with its accompanying payment of a bride price to the woman's family) and kinship (giving birth to children). Nigerian women are expected to endure, to be submissive and their voices often passive both within and outside the domestic

⁵ Nigerian HIV-AIDS activist Yinka Jegede-Ekpe describes her work, <https://www.facinghistory.org/resource-library/video/yinka-jegede-ekpe>

sphere (Makama 2013; Bako and Syed 2017).

2.2.1 Patriarchy, women and power

According to the literature, it is structural factors, notably patriarchy and gender inequality that have increased women's vulnerability to HIV and have the same time, have silent women (Ogunniyi and Dosunmu 2014). For Nigerian women in particular, these issues are deeply entrenched and have significant implications for women's emotional, physical and economic wellbeing. Klass et al (2018) state that in a patriarchal culture where men are seen as dominant and superior to women, women are unable to protect themselves from HIV and its impact. For example, the National Agency for the Control of AIDS (NACA) of Nigeria note that due to poverty in a country where about 70 percent of Nigerian women live on less than \$1 a day, most Nigerian women and girls lack the power to control key aspects of their lives including negotiating sex safe and marriage.⁶

In her book, *Daughters of Anowa*, the Ghanaian-Nigerian author Mercy Odudoye contends that patriarchy is pervasive in African society and discourages individuality and freedom of expression while encouraging uniformity and conformity. She argues that patriarchy was entrenched by colonial rule, which was essentially a European male creation that was largely reliant on, and driven by African men. In exercising their power, the new colonial patriarchy effectively sought to silent women and to create a new social order where women had to rely on men to provide them with economic capital which was necessary for survival in the emerging economies that African societies were forced to navigate during the colonial era (Maju et al 2019). Gbaguidi (2018) argues that there is no difference between western colonialism and African patriarchy since both led to the marginalisation of women in the society.

Some researchers have contended that patriarchy has been used to justify and perpetuate the 'inferior' position of women to render them financially dependent on men and to strip women of their social, economic, cultural and legal rights. For

⁶ Women, Girls, Gender Inequality and HIV in Nigeria, Factsheet 2016: [Fact-Sheet-Women-Girls-Gender-Equality-and-HIV-in-Nigeria.pdf](https://naca.gov.ng/wp-content/uploads/2016/12/Fact-Sheet-Women-Girls-Gender-Equality-and-HIV-in-Nigeria.pdf) (naca.gov.ng)

example, writing of the black American female experience, Hill Collins (2002:21) states that black women have been oppressed by society in a number of ways, defining oppression as 'any unjust situation where, systematically and over a period of time, one group denies another group access to the resources of society.' She also notes that oppression on the basis of race, class and gender have converged to shape the relationships that women of African descent have within their communities, with their families, employers and with one another. She also noted three key dimensions to oppression faced by black women in the United States which can also be applicable to black women elsewhere- exploitation of black women's labour which has rendered them vulnerable to low wages and poverty, the political dimension of oppression which has denied African descent women rights to the same privileges accorded to men and lastly, racist ideologies which are attached to black women. Historically, black female voices have been missing from leadership, in research and in academia due to the low status accorded to black women (McLane-Davison 2016). Hill Collins (2002) states that despite the history of oppression that African-American women have endured, they have sought to produce social thought designed to resist oppression, forms of which include creating women's only social groups, literature and music and arts designed to demonstrate the power and perseverance of black women.

2.2.2 Feminism and women in Nigeria

In a patriarchal society, HIV/AIDS has had a disproportionate impact on women in Sub-Saharan Africa. In such a society also, women's voices can also go unheard. The Nigerian novelist Flora Nwapa notes in her book, '*Women are different*', that Nigerian society expects women to remain silent and dutiful even when distressed. In Nigeria, marriage is an expected milestone for women and their primary means of identity yet it has elevated their risks for contracting HIV (Orisaremi 2017). Some feminists have argued that this is because men hold greater political, social, economic, cultural and symbolic power in marriages. Noyes (2017) argues in an article that marriage evolved 'as a way for men 'to protect' the women and children they considered to be their property, by essentially granting men ownership rights.' She further argues that patriarchal power has been enacted and reproduced through

cultural norms regarding female sexuality, marriage and motherhood where women are expected to give up their name, personhood and property upon marriage. Noyes (2017) notes in her article that women are also expected to comply with their husband's sexual demands, tolerate his infidelity and are dissuaded from negotiating safe sex with their spouses.

In Nigeria, women's ability to achieve agency is limited by gender and the social, economic and political realities that they face- something that this researcher is also familiar with. Nigeria is a society where male supremacy remains deeply ingrained and men are positioned as 'heads', with superiority over women (Adimula and Ijere 2019). Women are expected to play active roles in the domestic sphere but remain invisible in the external realm. Language has been used as a tool used to reduce the humanity of women. In both internal and external spheres, male superiority is emphasised. In recent years, there have been debates about patriarchy, feminism and the role of women in Nigeria, with religious interpretations of these issues dominating the debates. It is generally women from Southern Nigeria who have largely taken the lead in debating women's rights yet it must also be stated that feminism in Nigeria is not understood in the same way as it is in the global North.

Many Nigerians consider feminism irrelevant and a western import and some Nigerian women have themselves rejected the notion that they are feminists (Salami 2013). Salami (2018) has posited that Nigerian feminists contribute to the feminist movement as black/African women rather than as Nigerian feminists; they view feminism within pan-African lenses rather than through a Nigeria-specific perspective and as such, Nigerian feminism is not easily definable. However, there is an emerging Middle Class in Nigeria that is driving change and they have embraced new technologies in creating awareness about social issues affecting Nigerian women such as child sexual abuse, female illiteracy, sexual exploitation of women and domestic violence. Salami (2018) contends that Nigerian feminism may not necessarily be as inclusive as it appears. As an example, she points out that despite the adoption of western values, Nigeria remains a conservative society with pronounced gender roles and expectations for women, something that Nigerian women themselves have sometimes embraced, seeing it as a choice rather than an obligation. Few Nigerian women identify themselves as feminists and Nigeria itself is

a nation split along social, economic, cultural and religious lines. Feminism is strongly associated with rebellion and radicalism, something that unacceptable to African women (Nwanna 2012). Feminism is widely misunderstood in Nigeria because it is a term that is difficult to define- feminism is a complex topic that goes beyond notions of male/female issues and debates on feminism also touches on cultural and religious issues.

2.2.3 HIV as a structural discourse: applying a feminist lens to the study

Collins (2019) argues that gender should not just be theorized only in terms of male-female but rather, should also be conceptualized through intersectionality. Nakano Glenn (2002:8) contends that 'major areas of life, including sexuality, family, education, economy, politics are shot through conflicting interests and hierarchies of power and privilege along gender lines.' In this sense, these scholars have also called for HIV to be understood through gender lenses-, i.e., women are highly vulnerable to HIV due to their gender alone. In a shift from feminism, Watkins-Hayes (2014: 431) notes that 'HIV/AIDS is an epidemic of intersectional inequality that is fuelled by racial, gender, class and sexual inequities at the macro-structural, meso-institutional and micro-interpersonal level. These inequalities significantly shapes the likelihood of exposure to the virus; the realities of living with the infection and medical programmatic, political and social-scientific responses.'

Raj et al (2020:2) suggest that intersectionality is useful in highlighting 'the complexity and multidimensionality of people's lives, and posits that the social oppression they may experience actually originate from an intersection of different social inequalities and oppressive identities rather than from a singular marginalized identity.' They also note that intersectionality 'acknowledges how such intersectional dynamics between different social inequities and identities are contextual and may change over time and be different in different cultural and geographical settings' (Raj et al 2020:2). McKinzie and Richards (2019) introduced the notion of 'context-driven intersectionality' where they suggest the need to pay attention to the historical, political, social and economic factors that shapes power relations and social structures. They suggest that racism, social class, patriarchy, gender, disability, power, sexuality, etc., are contextual factors that are not mutually exclusive but can

interact with one another to generate structural advantages or disadvantages that shapes lived experiences in different ways, depending on their social location.

Although my present study is not an intersectional study per se, I have engaged in the debates in proposing to apply a feminist lens with context-driven intersectionality to the emerging study. McKenzie and Richards (2019) suggests that a context-driven intersectional lens allows for a better understanding of the complexity of the world in which the individual is situated in, by reflecting upon how social domains such as age, gender, class and power are both mutually constituted and intersect. Nigerian women are at the intersection of gender, power, discrimination and poverty and are particularly vulnerable to HIV. As the HIV/AIDS epidemic progresses, researchers have sought to understand and to address people's experiences of HIV itself including the complex and multidimensional factors which have increased people's vulnerability to HIV, particularly for young girls and women (Underwood & Schwandt 2016; Arije et al 2021). With reference to context-driven intersectionality, WLWH in Nigeria can be seen as a group of people living with multiple layers of marginalization that serves to disempower them in different ways. As this chapter has already noted, Nigeria's social and gender inequalities are partly rooted in the wider African colonial and post-colonial historical and social factors which have increased women's vulnerability and response to HIV infection.

Applying a feminist approach with a context-driven intersectional understanding to my research also involves recognising the historical context surrounding participants' experiences of living with HIV- Nigerian women have historically been disadvantaged by their gender, race and history of colonialism, which have had a profound influence on notions of gender equality in Nigeria today. As the findings from my study will demonstrate, an analysis of participant histories and experiences highlights the inequities that have disadvantaged them as women and have increased their vulnerability to HIV. These inequities often intersect with each other and include issues such as poverty and gender based discrimination. Gender inequalities have increased women's vulnerability to HIV and is a threat to women's biographies. In a social setting where HIV/AIDS is framed within a judgemental and moralistic discourse, being diagnosed HIV positive is often considered a traumatic life experience that may be experienced as a threat to one's survival, dignity and identity

(Kutnick et al 2017; Horter et al 2017; Diaz Payan 2019; Madiba 2021). Orsini and Kilty (2021:1139-1140) note that ‘people are transformed by illness and specifically by the temporal march that is characteristic of chronic illness. A new diagnosis can disrupt day-to-day life and change how we understand ourselves, our bodies and our minds, and our relationships to other.’ Bury (1982) has termed chronic illness as a ‘biographical disruption.’

2.3 Biographical Disruption: an overview

In the introductory section of this thesis, I introduced my relative’s experience – this was important in setting out the theoretical framework for this thesis because an HIV diagnosis disrupted his anticipated life course. Biographical disruption was first used by Michael Bury (1982) to describe a process whereby a significant or sudden event changes the course of an individual’s life and biography. Biographical disruption changes the direction of an individual’s life, altering their plans and hopes. In his own study, Bury (1982) provides a compelling and at times, moving account of individuals living with rheumatoid arthritis.

Bury (1982) used semi-structured interviews to study the experiences of thirty male and female participants aged between 25 and 54 years of age who had been diagnosed with rheumatoid arthritis and he proposes that chronic illness is biographical disruption because it is an experience in which the structures of everyday life are disrupted. Bury (1982:169) posits that,

‘My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally seen only as distant possibilities or the plight of others.’

Bury (1982)'s study highlighted the complex ways in which chronic illness⁷ forces an individual into a fundamental rethinking of their biography and self-concept. He further contends that chronic illness disrupts the structures of daily life and the forms of knowledge, which underpins these structures. He used the term, 'biographical disruption' to describe the disruption that takes place as result of chronic illness and in particular, he points to three crucial elements of this disruption,

'First, there is the disruption of taken-for-granted assumptions and behaviours.....Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental rethinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilization of resources in facing an altered situation. In addition, it brings individuals, their families and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. The growing dependency involved in chronic illness is a major issue here. Further, the expectations and plans that individuals hold for the future have to be re-examined (Bury 1982:169-170).'

Bury (1982) has proposed that the onset of chronic illness can disrupt the structures of meanings and social relationships by making the sick patient dependent on others for support. He refers to examples from his own study where the participants saw chronic illness not only as a burden but also as an 'assault' on their biography or identity, particularly with regards to their relationships with other people because it can lead to dependency on others, which he highlights as a major issue in chronic illness. Bury (1982) argued that chronic illness can have a disruptive effect on social relationships and practical affairs; it is not only just the individual who is affected but also their families and significant others. The participants in Bury (1982:169)'s study noted that chronic illness forced them to depend on others, thus disrupting 'normal rules of reciprocity and mutual support.' Moreover, Bury (1982) also notes that

⁷ Chronic illness has been defined as illnesses that have a long duration, generally progress slowly and do not have a cure (David Beran: Health Systems and the management of chronic diseases: lessons from Type 1 diabetes: *Diabetes Manage.* (2012) 2(4), 323–335)

chronic illness forces the patient to confront pain, suffering and even the possibility of death.

Bury (1982) also explored the concept of disclosure and uncertainty in the experience of chronic illness and he illustrates the ways in which chronic illness brings an awareness of the body through which the individual is forced to recognise a new world that is filled with pain, suffering and even the possibility of death, something previously seen as a distant possibility or something that happens to others. Bury (1982) further proposes that chronic illness can also bring fear and anxiety about the impact and course of chronic illness. Moreover, chronically ill patients often search for meanings in an effort to create effective coping mechanisms. In short, Bury (1982) suggests that chronic illness not only affects the physical body but also the trajectory of one's life on multiple levels. Individuals who try to make sense of the onset of chronic illness typically do so by locating it within the context of their previously untroubled life. It is in this sense that chronic illness can be understood to be a biographical disruption. Bury (1982)'s notion of chronic illness as biographical disruption also highlights the importance of strong social networks and the mobilization of resources in dealing with chronic illness.

2.3.1 Women, Chronic Illness and Biographical Disruption

Bury (1982) did not give due consideration to gender in his study but some recent studies have shown that chronic illness and biographical disruption are constructed and experienced along gendered lines. Clarke and Bennett (2013) note that notions of masculinity and femininity influence people's experience of chronic illnesses. Unlike men, women are socialised from an early age to be selfless, caring and sensitive to the needs of other and as a result, they frequently downplay their own suffering and pain. Women tend to reassess their relationships with their bodies, sense of self and the wider social world during chronic illness episodes. Similar to Bury (1982)'s notion of chronic illness as a disruption, Facchin et al (2017) suggested in their study of women who have endometriosis that chronic illness can interfere with multiple aspect of women's lives including their relationship with others, with many feeling that their experiences of pain were misunderstood by friends, colleagues, family members and doctors. Chronic illness can affect women's sense

of identity and can force them to alter their everyday life to deal with chronic pain (Facchin et al 2017). Clarke and Bennett (2013: 3) have suggested that 'women's experiences of chronic illnesses are also firmly embedded in and influenced by their various roles and responsibilities.'

Similarly, a study from the United Kingdom explored women's experience of biographical disruption in the context of sex and intimacy, fertility, professional and social lives. Using thematic decomposition with open-ended survey responses and interviews, the researchers found gendered expectations about femininity and sex influenced women's experiences of biographical disruption, with many women describing their feelings of guilt on the impact of endometriosis on their sexual life (Hudson et al 2016). Endometriosis was of particular concern to women from ethnic minorities because motherhood is a socially expected role, which affects their sexual life through disruption brought by pain, which limited their ability to initiate sexual intimacy with their partner. The researchers noted that for these women, endometriosis was particularly disruptive because 'this disruption carried with it feelings of guilt, failure and responsibility. In some cases, women also spoke of the feelings of loss for their partner and for extended families' (Hudson et al 2016:727). Hudson et al (2016) observed that overall for women, the disruption caused by endometriosis is experienced in conjunction with relational identities and gendered cultural expectations.

Wedgwood et al (2020) have suggested that ethnic, race, culture and other contextual factors shapes experiences and responses to biographical disruption. Despite gender being an important social construct that shapes people's sense of self and their biographies, very few research studies have provided an in-depth analysis of gender and biographical disruption. Those that have done so have reported that it has a profound impact on women's socially constructed roles. For example, one study on the impact of infertility following cancer treatment in Australia found that infertility had a profound impact on women's life course and sense of identity. Infertility was particularly disruptive for women, 'for whom biological motherhood stands as a core signifier of adult femininity, with infertility positioned as failure to fulfil the role of 'good wife' and 'mother'' (Ussher et al 2018:2).

Two studies from the global South (Brazil) and one from the global North (United States) explored the notion of biographical disruption in the context of structural factors. In Brazil, the authors of a study of a group of women who are mothers of children with congenital zika syndrome reported that, 'we identified that the arrival of a child with disabilities resulted in biographical disruption similar to that experienced by people with chronic illness' (De Melo et al 2020:2). Public health policies aimed at controlling the zika virus placed the burden of prevention solely on poor women even though the state has failed in its duty to eradicate mosquitoes which spread the virus. Coutinho et al (2021) note that through poor urban planning, the Brazilian state has failed to provide access to adequate homes, clean water and adequate health services for its citizens, with women bearing the greatest impact.

The lack of an effective public health policy to control the zika virus, 'when observed through the lens of gender and socio-economic inequalities, disproportionately affect women' (De Melo et al 2020: 2). Although the women in the study were themselves not ill, their children's disabilities meant that their own lives were fundamentally altered – their behaviours and assumptions had to change in order to address the uncertainties their children's disabilities brought (De Melo et al 2020). They also had to reorganize resources to deal with these disabilities. The Brazilian state and men rarely appeared in the women's narratives. Instead, uncertainties took on a gendered construction where women adopted socially constructed roles as mothers and carers tasked with the huge (and often sole) responsibility of caring for disabled children. Help came mainly from other women such as sisters, mothers, grandmothers and mothers-in-law (De Melo et al 2020). Castro et al (2018) noted that for mothers of children with congenital zika syndrome, their children's disabilities had already intersected a biography of frequent disruption including deepening poverty, racism against Afro-Brazilian women and discrimination.

The other study was carried out in Thailand. Using a qualitative approach situated within a feminist framework, Liamputtong and Suwankhong (2015) investigated the experience of biographical disruption among a group of 20 Thai women diagnosed with breast cancer. As breast cancer is a leading cause of death in Thai women, a breast cancer diagnosis was a traumatic event for these women, for whom it triggered thoughts of death and dying because they thought they would die soon.

This disruption occurred when they received their diagnosis, with participants reacting with shock, fear and disbelief at their cancer diagnosis. The study suggested that receiving a cancer diagnosis disrupted the women's previously held assumptions about their lives and their plans for the future, not least because it was unexpected. In the absence of better understanding about the women's needs and concerns relating to breast cancer by healthcare providers, the participants had to rely on their own emotional strength and religious beliefs and practices to deal with their health situation and to devise their own coping strategies. The participants saw breast cancer as a fate that they had to accept and live with, a belief linked to their Buddhist beliefs. Buddhism provided emotional support and relief to enable the women deal with the chaos and despair they experienced because of their breast cancer diagnosis. In capturing the participants' accounts of breast cancer, the researchers acknowledged that the women themselves were expert sources of knowledge about their own experience. The research also suggested that the participants had to find a way to cope with breast cancer by devising their own strategies, as their health provider was ill-equipped to provide supportive services beyond biomedical treatment.

Lastly, a study from the United States found that structural factors influenced the participants' experiences of chronic illness. Although the subjects were not women, the study was particularly useful, as it applied a structural intersectional framework with biographical disruption to show how HIV positive black gay and bisexual men are at the intersections of multiple axes of structural oppressions that left them at risk of contracting HIV and experiencing biographical disruption (Campbell 2021). The men had already experienced stigma and discrimination including rejection and lack of support from family members as a result of their sexuality; some had traumatic childhood experiences involving physical and sexual abuse, often from their own family members. An HIV diagnosis was a major disruption for the majority of the participants, resulting in discredited definitions of self, disruption to already strained social and familial networks as well as socioeconomic and structural impacts, as HIV diagnosis and disclosure resulted in economic instability for the men. Campbell (2021) noted that black gay and bisexual men are located at the intersections of race, class, geography, sexuality and HIV status, which made them particularly vulnerable to disclosure-related biographical disruption. Contrary to the positive

notions of disclosure promoted by health providers, the men who had negative experiences of disclosure described it as a disruption that manifested in multiple ways with one disruption often leading to another.

2.3.2 Biographical disruption in non-western context

Most studies on biographical disruption have been carried out on subjects living in the global North and these have tended to suggest that the experience of biographical disruption is an individual one that is experienced by the individual. By contrast, studies from the global South have reported that chronic illness is experienced as a biographical disruption which impacts entire households, as noted from the study from Brazil already cited above. Pesantes et al (2020:381) studied the experiences of chronic illness as biographical disruption in Mozambique, Peru and Nepal and noted that,

‘despite the differences among the countries, people’s daily lives, interpersonal relationships and family dynamics were similarly disrupted by chronic conditions. Having a chronic condition translated into a reduced capacity to fully participate in work and household activities that in turn impacted their families..... The economic implications of chronic condition management constituted stressful experiences for our participants as limited disposable income and financial means are not available to purchase different types of food or paying for necessary medications. Furthermore, adaptive strategies were also limited because in these countries there are no public-sponsored support schemes for unemployment or disability. Ill-health in these settings results in the disruption of the lives of other family members who need to step in to sustain the household.’

The experience of chronic illness resulted in change and reconfiguration of social roles and responsibilities. Although the study did not add a gender lens, the researchers nevertheless acknowledged that for women in particular, the inability to fulfil gender roles was a source of additional distress, with many expressing feelings of guilt and self-blame and feeling that they had failed in their responsibilities as wives and mothers (Pesantes et al 2020).

Whilst a study of a group of unmarried young women aged 16-28 living with HIV in Burkina Faso, West Africa did not focus extensively on chronic illness or biographical disruption, Ouedraogo (2012) noted that the experience of biographical disruption for these women was just as profound. Upon receiving an HIV diagnosis, the women experienced a shattering of self, a form of biographical disruption, which introduced the notion of 'before' and 'after' HIV into their life course. HIV undermined the women's image of their self as well as their relationships with other people within their social world. HIV was experienced as a biographical disruption which touched upon the key markers of femininity, notably marriageability, moral values and procreation, with many of the young women believing that HIV had undermined their sense of identity. In a society where marriage is a key source of identity and marker of adulthood, HIV positive women are at particular disadvantage. HIV led to uncertainties concerning the trajectories of these women's lives by putting question marks on their desire for marriage, normality, health and economic stability.

2.4 HIV: a chronic illness of difference

HIV is noted as a disease of difference. Arrey et al (2015:2) state that 'a striking difference between HIV and other chronic illnesses is that HIV is highly infectious and predominantly transmitted through sexual contact. HIV is still not accepted as a 'normal' chronic disease, making HIV/AIDS patients vulnerable, stigmatized and disinclined to disclose their disease.' In this sense, it seems appropriate to consider HIV as a form of biographical disruption. Although it is considered a chronic disease, HIV has other characteristics that differentiates it from other diseases. Firstly, HIV is both chronic and acute- the latter occurs when persons with HIV experience non-AIDS related morbidities such as cancer or cardiovascular diseases (Davy-Mendez et al 2018).

Secondly, HIV is a chronic illness that has profound social, cultural and economic impacts (Mabaso et al 2019). Once seen as a fatal illness, HIV infection has become a chronic condition for individuals with access to good healthcare and treatment in the global North. The introduction of antiretroviral therapy (ART) has proved to be lifesaving and has extended life for people living with HIV in the global North. Wouters (2012) suggests however that in other parts of the world with resource

limited settings including much of the African continent, the HIV/AIDS epidemic continues to have a devastating impact on family and social networks, communities, public services and national economies.

Thirdly, HIV itself is a challenging illness, for which patients must take medication for the rest of their life. Some studies have reported that some patients experience difficulties with taking HIV medications and that HIV medications have side effects ranging from the mild to severe, which can make some people stop taking them (Gagnon & Holmes 2016; Gagnon & Homles 2016; Renju et al 2017). Although medication has made HIV a manageable illness, persons with HIV may be left with the physical manifestations of their HIV status such as facial lipodystrophy or skin sores, which may mark them out as people living with HIV (Alexias et al 2016). Through HIV medication, women can become medicalised individuals for whom HIV is played out through bodily experiences. People with HIV experience stigma, poverty and must take medications for the rest of their life and women in particular are at risk of life trajectories with stigma and poverty as well as experiencing treatment challenges which are often associated with poor outcomes (Johnson et al 2015).

2.4.1 HIV and stigma

The literature on HIV suggests that living with HIV is a painful and stressful experience for Nigerian women which results in severe emotional and psychological distress for women, bringing feelings of depression, loss of self-worth and fears of stigma (Adamu et al 2019). As HIV is commonly judged to be a sexually transmitted disease, when a woman is diagnosed with HIV, she is labelled and treated with suspicion and her moral values are questioned (Halimatusa'diya 2019). The moralistic and judgmental discourse that surrounds HIV has had a profoundly negative effect on women's ability to move with life with HIV (Bala et al 2022). HIV positive women are at particular risk of encountering stigma, which can be a very painful experience. Since its articulation by Goffman (1963), stigma has been defined as 'an attribute that is significantly discrediting.'

Parker and Aggleton (2003) have argued that whilst Goffman (1963)'s definition of stigma has been useful in providing a basis for research studies on stigma and HIV,

there is a need to apply some caution because in their view, stigma goes beyond an 'attribute' that is 'discrediting.' In particular, they emphasize that stigma is not a static characteristic and should be 'understood in relation to broader notions of *power* and *domination*. In our view, stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, stigma is linked to the workings of *social inequality* and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings.'

Kemp et al (2019:1151) have noted that 'HIV stigma is the co-occurrence of labelling, stereotyping, separating, status loss and/or discrimination associated with HIV in the context of power imbalance. HIV stigma has several dimensions.' Writing extensively on stigma, Goldberg (2017:475) states that 'stigma is corrosive. It is capable of causing intense psychological harm.' Goldberg (2017:475) also writes that 'as stigma scholars note, the definition of stigma is inextricably linked to power structures, which means that stigma strongly tracks social inequalities: disadvantaged groups are more likely to be stigmatized than privileged groups.' Goldberg (2017) further notes although stigma may be manifested through individual encounters, the foundations of stigma are firmly rooted in the larger social structures which points to a connection between social power and inequality, i.e., the less social power an individual or group have, the more likely they are to encounter stigma.

As women hold little power compared to men, women living with HIV bear what Paudel and Baral (2015) have described as 'triple jeopardy' in living with the impact of HIV: as people infected with HIV, as mothers living with HIV which may also include caring for HIV infected child or children and as carers of other family members with AIDS. Kemp et al (2019) have additionally noted from their study that women of African descent living with HIV have multiple layers of marginalized identities at the intersection of race, gender and health, which leaves them vulnerable to HIV stigma. With particular reference to Nigerian women, their

experiences of HIV-related stigma has been intensified by their limited control and power over financial, reproductive and social resources (Adimula and Ijere 2019).

HIV can complicate how women view themselves as well as their friendships and relationships with others (Liamputtong 2013). Due to the stigma associated with HIV, HIV positive women are at risk of social, economic and cultural exclusion, particularly in collectivist societies. Iwelunmor et al (2017) have noted that Africans have a predominantly collectivist outlook and tend to conceptualize their identity in collective terms, conceiving themselves in relations to other members of their society. In such a society, women living with HIV take steps to conceal their HIV status in an effort to protect themselves and members of their family from stigma and gossip. Through stigma, women living with HIV are subject to shame, rejection and labelling (Iwelunmor et al 2017). As one Nigerian woman states of stigma in Nigeria in a recent newspaper article, 'as long as the society is concerned, once you have HIV, you have become a working ghost.'⁸

Studies have suggested that stigma against HIV positive women results from the widespread perceptions of HIV as a sexuality transmitted disease. A report from South Africa where women account for 60 percent of PLWH found that women diagnosed with HIV are considered irresponsible, promiscuous and dangerous and they face discrimination and rejection from the wider society. The report by Woodward (2014) noted that there is a 'connection between the stigmatization of HIV and the stigmatization of female women, specifically the stigmatization of female sexual desire. When these gender stigmas interlock, such as with HIV positive women in South Africa, a general devaluation of women in many societies occurs.' Other studies have also reported that negative attitudes towards HIV positive women are quite common (Armstrong-Mensah et al 2019; Kontomanolis et al 2017).

HIV stigma is sometimes considered to be a manifestation of the unequal social structures that have evolved since the beginning of the HIV/AIDS epidemic; Parker & Aggleton (2003) have noted that the complex socio-cultural connections around HIV makes it difficult to fight against HIV stigma even though the experience of stigma

⁸ Nike Adebawale (2019), 'How stigma is affecting HIV treatment in Nigeria', [How stigma is affecting HIV treatment in Nigeria \(premiumtimesng.com\)](https://premiumtimesng.com)

shapes the wider experience of living with HIV. At least one study has noted that stigma has meant that women are generally less likely than men to disclose their HIV status, leaving them more vulnerable to isolation (Loutfy et al 2016). Isolation can lead to loneliness, which can disrupt the structures of everyday life. HIV can radically alter the life course, leaving people searching for personal meaning in an effort to make sense of changed circumstances. Women living with pain due to chronic illness have often described their experience as a lonely condition (Cole et al 2020). Morgan and Burholt (2020) state that ‘loneliness can dislocate an individual’s sense of self their assumptions about the world, and their relationships as well as unsettling their plans, resulting in questions such as ‘what has happened to me?’, ‘who have I become?’ and ‘why.’ Visser (2012) notes that society is often less tolerant of HIV positive women than of HIV positive men, leaving them to question themselves in the context of a positive HIV diagnosis.

2.4.2 HIV and Poverty

Studies on African women living with HIV have found that they are also at particular risk of discrimination and violence because of their HIV status (Colombini et al 2016; Meskele et al 2021). A recent study has found that the life trajectory of HIV positive Nigerian women is marked by one of extreme poverty and HIV positive women are disproportionately vulnerable to poverty; living with HIV is challenging for women and their daily struggle to survive is exacerbated by poverty (Maju et al 2019). A similar study from Kenya noted that systemic inequalities that originated from the colonial period have affected women’s lives and have pushed women to the margins of society. The women spoke of looking after themselves and their children while sick and living in poverty and of the support they received from other women, particularly their female relatives- no woman spoke of receiving any form of support either from the men in their lives or from the state (Van Tyler and Shields 2015).

According to the World Bank, oil accounts for 80 percent of Nigeria’s exports and Nigeria is highly vulnerable to decline in oil prices and oil revenues. Nigeria’s current GDP of \$2,097.10 ranks it as a low-income economy and forty percent of Nigerians (83 million people) live below the poverty line⁹ with women constituting over 60% of

⁹ GDP per capita, <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD?locations=NG>

the poorest people living in Nigeria (Onwuka et al 2019). Fewer opportunities for employment and education have prevented empowerment of women, which in turn restrict access to healthcare, jobs and education, leaving women particularly vulnerable to risk behaviours to HIV such as transaction sex and substance abuse. Studies have shown that for PLWHA, poverty can amplify poor treatment outcomes (Adamu et al 2018; Aliyu et al 2015). Where women are in employment, they are more likely to work in low-paid and low-skilled casual jobs; are less likely to be educated and culturally, they cannot inherit landed property- women are culturally regarded as property to be inherited alongside their husbands' property (Kuteyi 2013). In Nigeria, HIV and poverty are intertwined and poverty is a key driver for the spread of HIV/AIDS, particularly among young women (Best and Alubo 2017).

Poverty has impacts on women's experiences and options in living with HIV and can leave women particularly vulnerable to exploitation. For example, some treatment providers in Nigeria employ a large number of HIV positive women on low wages on condition that these women disclose their HIV status to others in return for job opportunities, although as Dlamini-Simelane (2017) suggest from experience in Swaziland, this exploitation may be due in part to lack of government funding for treatment programmes.

2.4.3 HIV and medication

There is no cure for HIV but it can be treated with drugs, which has enabled people with HIV to live a healthy life. HAART (highly active antiretroviral therapy) is the medication used to treat and manage HIV and is composed of different types of drugs (Eggleton and Nagalli 2021). HAART is also known as ART (antiretroviral therapy) or ARV (anti-retroviral). The main aim of ART is reduce the concentration of the HIV virus (viral load) to an undetectable level, thereby slowing the progression of HIV to AIDS. However, for this aim to be achieved, the patient must adhere correctly to their medication as prescribed by their treatment provider. There are different types of HIV treatment regimens, some of which may involve a combination of different types of medications and each of these medications may have its own specific requirements. Some patients may take one drug two or three times a day,

with or without food while other patients may have to take up to eight drugs a day.¹⁰ Regardless of the type of treatment, patients are required to take their ART drugs at the same time on a daily basis for the rest of their lives and with the right treatment, PLWH can live a normal life. Failing to adhere correctly to ART can lead to treatment failure, which can cause the virus to mutate and lead to drug resistance, potentially posing a danger to the patient's health and life (Heestermans et al 2016).

One of the main benefits of treatment is that it has enabled some PLWH to attempt to 'normalize' their lives in living with HIV even in the face of uncertainty over the progress of HIV illness, which they have little or no control over. Wekesa and Coast (2013: 5-6) noted in their study that ART has had a positive effect on the self-identity of PLWH by improving their 'capacity to work, important for social and economic viability and validation, allowing people to play their societal role as breadwinner, parent or adult.' Nevertheless, ART has some unpleasant side effects which varies from person to person and may include shingles, unwanted weight gain, fat loss and nausea (Nanseu and Bigna 2017; Taramasso et al 2017; De Wet & Wouters 2016).

Some studies report that women experience difficulties adhering to their treatment and that these difficulties are exacerbated by the social context in which ART is taken. A study of black West African women receiving treatment for HIV in London, UK reported that the participants found their medication onerous and difficult to swallow, with many describing their medication as a form of life imprisonment (Spiers et al 2016). Some participants in the same study also described a sense of feeling trapped by their drugs for the rest of their lives, leading to feelings of depression and hopelessness. This finding is similar to findings from another study from Uganda where women described ART as a 'tug of war' (Matovu et al 2012). For the participants, balancing everyday aspects of life such as school, domestic work and their social relations with others had an impact on their ability to adhere to their

¹⁰ Prior to 1996, the first combination drug therapy was difficult for patients with HIV to manage- these medications were highly toxic and involved patients taking as many as 4-5 pills every hour, with many side effects such as nausea, loss of appetite and vomiting. In 1996, a combination of HIV medications that could suppress the virus' replication and hence stop progression of HIV to full blown AIDS was introduced; advances in the treatment of HIV since 1996 means that some PLWH can be treated with a single dose that combines multiple drugs and endure fewer side effects. How HIV became a treatable, chronic disease <http://theconversation.com/how-hiv-became-a-treatable-chronic-disease-51238>

medication and many of the participants expressed concerns about the impact of stigma, discrimination and lack of love and support on adherence to ART.

Similarly, Nicholls et al (2021) presented an analysis of black African and black Caribbean women's experiences of adherence to ART in the UK. Their study focused on the embodied and adaptive aspects of adherence to ART and illustrated the tensions and ambivalences the women experienced as they attempted to resolve bodily experiences that compete with clinical expectations of adherence. The authors highlighted how adherence was grounded both in everyday practices and in 'hinterlands' of historical, political, geographical and social connections to care. The women lived precarious lives in the shadow of worries about their immigration status, mental health issues, homelessness and domestic violence and the authors noted that these women, in common with black people in the UK, are disproportionately affected by poverty and uncertainties related to their immigration status and low employment and pay.

A study of HIV positive women in Zambia found that HIV affected their daily lives and taking ART was the clearest reminder of their HIV status and an unwelcome one at that. The very repetitive nature of ART was such a constant reminder that many women stopped taking their drugs; some of the women had difficulty in keeping their HIV status secret and HIV had an impact on their familial and sexual relationships and their friendships. Some went great lengths to hide their drugs from others. For these women, 'their bodies, their illness and their health are inextricably tied to their close family histories as well as wider bio-medical developments' (Mackworth-Young et al 2020:164). For women from the global South in particular, it is clear that women's HIV infection and their survival are linked to ART availability and the unspoken expectation is that women have a responsibility to take their ART to bring their viral load to undetectable levels, thereby protecting others by preventing the spread of HIV.

Even with medication, HIV positive women have struggled to conform to idealized social image of womanhood- HIV/AIDS remains a highly stigmatized, much maligned and misunderstood illness. Medication does not reduce stigma, as even when healthy, WLWH are sometimes confronted with physical manifestations of their HIV status, which can have some profound psychological impacts. Such manifestations

includes but are not limited to deafness, loss of sight and weight gain. African women still have to negotiate the multiple social and psychological challenges of HIV including poverty, stigma, disclosure, rigorous adherence to ART. In addition to this, there are currently question marks over the long-term sustainability of free ART programmes in many African countries, in the light of a scaling down of international donor commitments (Oberth and Whiteside 2016; Marten 2019; Lince-Deroche et al 2019). For example, Itiola and Agu (2018) note that the Nigerian government funds only 23% of its HIV/AIDS programme, with the rest coming from the international community. This potentially puts treatment at risk for PLWH and even at the time of fieldwork, this researcher noted that the treatment organisations were experiencing some shortage of drugs and the breakdown of some medical equipment due to lack of funding and they had to start charging patients for services such viral load tests that were previously provided free of charge as part of a fully comprehensive treatment programme.

2.5 Why Biographical Disruption?

The notion that chronic illness disrupts life structures, meanings, relationships and the management of practical affairs is one that has been highlighted by a number of studies on chronic illness including research studies on HIV (Alexias et al 2016; Maina et al 2016; Wouters and De Wet 2016). Unfortunately, Bury (1982) did not address the gendered nature of chronic illness and his study did not include samples from Black, Asian and Minority Ethnic backgrounds. Moreover, chronic conditions such as HIV are increasingly prevalent in low-income countries yet we still know so little about the experience of biographical disruption outside of western contexts, particularly among women. There is a gap in the literature which calls for additional studies on the experience of biographical disruption from non-western contexts and there is an additional need to consider the structural, cultural and gendered aspects of biographical disruption, something that Bury (1982) did not give particular attention to in his own study.

The gap in the literature on the gendered nature of chronic illness and biographical disruption also suggest that there is a need for research that focuses on the experience of African women living with HIV, particularly from West African subjects.

I have not come across any other study on chronic illness and biographical disruption involving West African subjects. In addition to this, very few studies have focused on structural factors that have influenced the experience of chronic illness as biographical disruption. Pesantes et al (2020) have stressed the need for additional studies that focuses on the experience of chronic illness with a gender lens. They suggest as well, chronic illness is not just a health issue but also one that has social and economic impacts, affecting the individual and their families. As noted in chapter 2.1 of this chapter, globally, Nigeria has the second largest number of people living with HIV/AIDS and Nigerian women are disproportionately infected with and affected by HIV/AIDS. As a group, Nigerian women are an under-researched group and there are few little qualitative research studies that contributes to the knowledge of how Nigerian woman live with a marginalized condition with reference to biographical disruption. I am undertaking this study in an attempt to fill the gap in the literature on the lived experiences of HIV positive Nigerian women.

In using biographical disruption to frame my own study, I would like to unpick the terms, 'biography' and 'disruption', something that Bury himself does not do. Tembo (2017) has noted that biography is an individual's life story, a recording of their life written by someone else and Alexias et al (2012) have described disruption is a 'rupture on the continuity of one's biography.' The words, 'biography' and 'disruption' used in the context of chronic illness refers to the notion that chronic illness interrupts or stops the progress of one's life and it can happen in several ways and have several impacts including stopping one's dreams or aspirations and could result in poverty, childlessness or even death. Disruptions through illness can have an impact on a person's ability to carry out their social roles. Hudson et al (2016) state that disruption may be culturally derived, a view that I find particularly relevant to my own research because there are few studies on how HIV may affect the expected biography of some Nigerian women. In unpicking women's experiences of HIV, I am proposing that biographical disruption will enable me to explore how women navigate life in the context of HIV and the contextual factors that have impacts on these experiences such as poverty and stigma. HIV positive Nigerian women at the intersection of gender, poverty and HIV.

2.6 A justification for the research

Existing recent literature on the experiences of Nigerian women living with HIV is limited, particularly with regards to the location – North-Central Nigeria and conceptual focus- HIV positive Nigerian women living with HIV with reference to biographical disruption. Moreover, the limited studies that exist have not applied a feminist lens to explore the experiences of HIV positive women from North-Central Nigeria. There is a need for such a study that takes into consideration issues relating to biographical disruption, gender and power and the wider contextual factors that impacts on the lives of HIV positive women from North-Central Nigeria.

Many of the policies I encountered in the treatment organisations that participants were recruited from are based on models adapted from the Global North yet these policies do not fully take into account the gender and power inequalities that exist in Nigeria. The Nigerian women in my research are African who are poor and HIV positive and these affects their experiences of living with HIV. Wider contextual and cultural factors also intersect their experiences, which suggests that applying a feminist lens to my research would provide a useful starting point in illuminating the experiences of Nigerian women are who living with HIV.

Summary

This chapter provides an introduction to the study by introducing statistical information on HIV/AIDS, patriarchy and society's attitudes have increased women's vulnerability to HIV. This section also highlighted the lack of research in women's experience of HIV during the early years of the epidemic. The second part of this chapter provides an overview of Bury (1982)'s notion of chronic illness as biographical disruption and offers some relevant literature with reference to women's experiences of chronic illness and biographical disruption, with particular reference to HIV as a chronic illness that differentiates itself from other chronic condition, with some discussion on stigma, poverty and medication. The chapter concludes with the rationale for the study and biographical disruption as the theoretical framework for the study. The next chapter discusses the research methodology adopted in carrying out the present study.

Chapter Three: Research Methodology: Interpretative Phenomenological Analysis

Introduction

In the earlier chapters of this thesis, the researcher emphasized that there is a critical gap in the literature on the lived experience of HIV positive Nigerian women and noted that they are under-researched and underrepresented in research studies. The present research seeks to address this gap in the literature and to provide as realistic as possible an account of how Nigerian women make sense of living with HIV. Unlike in the global North where HIV is a treatable chronic illness, a different reality of HIV prevails in Nigeria, a country that is highly vulnerable to global economic disruptions, despite its status as Africa's largest economy and oil producer. This chapter describes the research methodology used to address the research questions that were previously highlighted in chapter one ([see section 1.3](#)). The present chapter discusses the research design including philosophical traditions, methodology and research practice. The next chapter builds on from this by focussing on the research methods.

This chapter outlines and discusses the philosophical traditions that frames this research. Research studies are generally framed by ontological and epistemological standpoints: ontologically, Interpretative Phenomenological Analysis (IPA) has informed the present study with an interpretivist stance and epistemologically, the research adopts a constructivist stance in attempting to understand Nigerian women's experience of a phenomena (living with HIV). This chapter also describes the research methodology used in my research and discusses some of the key philosophical assumptions underpinning IPA research as well as the rationale for selecting IPA as a methodology.

3.1 Research tradition: qualitative research

In recent years, studies focusing on African women living with HIV have tended to focus on the experiences of black South African women and there is a gap in the

literature on Nigerian women even though HIV is prevalent in Nigeria. Most studies on HIV/AIDS in Nigeria are quantitative studies that have largely focused on the biomedical/clinical aspects of HIV/AIDS or testing people's knowledge, attitude and behaviour with reference to HIV/AIDS, with the majority of these studies focusing on Southern Nigeria (Odimegwu et al 2017). Quantitative research typically relies on numbers and statistical methods, to explain, describe, predict or control variables and phenomena. Mertler (2021: 92) notes that 'one of the underlying tenets of quantitative research is a philosophical belief that our world is relatively stable and uniform, such that we can measure and understand it as well as make broad generalizations about it.'

Qualitative research, on the other hand, 'is the study of the nature of phenomena, including their quality, different manifestations, the context in which they appear or the perspectives from which they can be perceived, but excluding their range, frequency and place in an objectively determined chain of cause and effect' (Busetto et al 2020:1). As the primary aim of my research study was to explore the experiences of Nigerian women living with HIV rather than answer specific questions about HIV/AIDS or its medical/clinical aspects, qualitative research methods are particularly appropriate for exploring human experiences.

To address the gap in the literature, I decided to apply a feminist approach to my chosen methodology, Interpretative Phenomenological Analysis (IPA). I applied a feminist lens to reflexivity to reflect on the wider contextual issues that affected my research including issues relating to power, poverty and other structural factors. IPA is a research methodology introduced by Jonathan Smith in 1996 as an alternative to the empiricist, positivist and paradigms that were widely used within psychology at the time. He intended IPA as a qualitative and experiential approach that would still engage with mainstream psychological research methods (Smith et al 2009). IPA has since become an established research method in health psychology and is widely used to explore a wide range of health issues such as cancer, HIV, diabetes, chronic back pain and infertility. IPA is a research methodology that particularly resonates with my research for reasons, which are discussed further in this chapter.

3.2 Introduction to IPA: What is IPA?

As Finlay (2012:17) states, 'there is a general consensus that we need phenomenological research methods that are responsive to both the phenomenon and the subjective interconnection between the researcher and the researched.' Smith was influenced by broadly phenomenological approaches in developing IPA as a research methodology. Finlay (2009:1) states that phenomenology emphasises a 'return to embodied experiential meanings aiming for a fresh, complex description of a phenomenon as it is concretely lived.' Finlay (2009) further states that phenomenologists have generally agreed that human subjectivity is an important part of the research process and is in fact the key to the research process in phenomenological studies- as a result, researchers need to be open to other viewpoints. Smith et al (2009:1) have described IPA as 'a qualitative research approach committed to the examination of how people make sense of their lived experiences of the phenomena under investigation.' The phenomena under investigation are typically experiences of personal significance, which are likely to influence the course of an individual's life. IPA takes an idiographic approach to phenomena by offering a rich and in-depth insight into how an individual or individuals make sense of the phenomena under investigation.

3.2.1 IPA: foundations of knowledge: Phenomenology, hermeneutics and idiography

IPA draws upon three philosophical areas of knowledge namely phenomenology, hermeneutics and idiography. Phenomenology is the study of the human experience that has its roots in philosophy (Holloway and Wheeler 2010). Smith and Osborn (2015:41-42) have stated that IPA is phenomenological in that it is concerned with exploring 'lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions and it recognises that this is an interpretative endeavour as humans are sense-making organisms.' Smith et al (2009:34-36) have emphasized in their definitive handbook on IPA research that it is an approach that is participant-oriented, that is, an approach very much concerned with 'the human lived experience, and posits that experience can be understood via an examination of the meanings which people impress upon it. These meanings, in turn, may illuminate the embodied, cognitive-affective and existential domains of psychology.' IPA has much

in common with other qualitative research approaches where the participant is seen as the expert and IPA focuses on the participant's sense of meaning-making, describing not only the phenomena/event under investigation but also the significance of this event for the participant, including the language they use to describe and make sense of the phenomena/event.

A key aim of IPA research is to unravel the meanings contained in accounts through a process of engagement with texts and transcripts (Smith and Osborn 2008). IPA focuses on the individual experience whilst also seeking to identify commonalities among other individuals sharing the same experience- it is for this reason that IPA studies often select a fairly homogenous group of participants. Smith and Osborn (2015:42) have argued that small sample sizes are of immense benefit to IPA, as it 'enables the micro-level reading of the participants' accounts, which offers the possibility of some entrée into the understanding of this elusive condition.' IPA is not just descriptive but also involves the researcher presenting an interpretive account of what the phenomena under investigation means for the individual (Noon 2018).

Smith et al (2009) have acknowledged that the development of phenomenology has led to overlapping and contradictory ideas as researchers and key thinkers have introduced ideas and concepts that have been applied and extended numerous times. They also acknowledge that there are challenges in merging traditional phenomenological philosophies with the practicalities of the collection, analysis and communication of research findings. As they have noted, 'human and health science researchers are not usually concerned with examining their own experiences but rather with attending to the experiences of others. Thus, the challenge for phenomenological psychology is to translate the insights of phenomenological philosophy into a practical but coherent approach to the collection and analysis of third-person data' (Smith et al 2009:33).

The second area of knowledge that IPA draws upon is hermeneutics. Hermeneutics essentially means 'interpretation' or 'the practice or art of interpretation' and involves 'the restoration of meaning' (Noon 2018). Smith et al (2009) introduced three key thinkers who have influenced IPA- Gadamer, Heidegger and Schleiermacher. Although Smith's approach is less descriptive than many other phenomenological approaches that follow descriptive phenomenology, he offers much more guidance

and flexibility than other hermeneutic approaches that I have come across. IPA analyses how experiences both converge and diverge whilst also retaining its focus on individual accounts. IPA studies tend to focus on interpreting human experiences of a specific phenomenon, with references to individual accounts of the phenomena under investigation (Alase 2017).

Smith et al (2009) have noted that IPA combines some aspects of both phenomenology and hermeneutics in its attempts to get as close as possible to the lived experience of each participant in a study and at the same time, tries to interpret the same experience from each participant's viewpoint. The researcher's own worldview and interaction with the participant is an important part of IPA research. As a result of this, the research analysis is the researcher's own interpretation of the participant's interpretation of the lived experience, a process that is called, 'double hermeneutic' (Smith and Osborn 2008) or as Smith et al (2009) describes it, 'the researcher is trying to make sense of the participant trying to make sense of what is happening to them' (Smith et al 2009:3). As I began to reach a better understanding of how IPA would apply to my own study, I found that 'double hermeneutic' aligns with my broader aim of exploring and gaining some insights into the participants' experience of living with HIV whilst also recognising my own impact as a researcher. It is for this reason that Smith et al (2009) call for the need for transparency in the research process, as IPA analysis is a subjective interpretation. To bring transparency to my study, I engaged in the process of reflexivity throughout my fieldwork, as can be seen from the notes from my research journal presented in chapter one of this research.

The third area of knowledge that IPA draws from is idiography. IPA studies have generally focused on small samples where each case is individually analysed and a shared picture of experience is captured across cases in the study, whilst retaining a focus on each participant's individual experience. No experience is the same but there are shared commonalities across samples. It is in this sense that IPA is idiographic- 'it emphasises detailed and in-depth examinations of how individual persons in their unique contexts make sense of a given phenomenon; it seeks to learn from each participant's individual story, and through a deep individualised analysis, a more informative understanding of participants' thoughts, belief and

behaviours is attainable' (Noon 2018:76). Smith et al (2009) state having a small sample size allows for a deeper and richer understanding of phenomena that would otherwise not be possible in larger samples. Moreover, too, focusing on a specific phenomenon utilizing a smaller sample allows for a better understanding of the phenomena being investigated, which works quite well with a feminist concern to give 'voice' to women's lived experience.

3.3 Limitations of IPA

Lastly, I address the limitations of IPA. During my viva, concerns were expressed about the small study sample, which I aim to address here. There have been debates about sample sizes in IPA research studies although it is worth noting that this is not limited to just IPA studies but also to qualitative studies in general (Vasileiou et al 2018). In recognition of its commitment to providing a deeper analysis and idiographic focus, IPA studies tend to have smaller sample sizes in comparison to other research methodologies. IPA sample sizes do vary and may have involve a married couple (McGregor et al 2014), three participants (Patel et al 2015), five participants (Muiruri et al 2019) while studies with more than ten participants are not uncommon (Dalvi and Mekoth 2017; Flowers et al 2011). Regardless of sample sizes, as Farr and Nizza (2019:211-212) have noted, IPA studies are more concerned with exploring lived experience of phenomena in a specific context and most have an idiographic focus. IPA studies generally provide 'detailed accounts of participant trajectories [which] revealed how a person's relationship with phenomena is dynamic, while also providing insights into how their distinct perspective evolves through an interplay of sense-making and time'(Farr and Nizza 2019: 211-212).

In addition, Charlick et al (2016) note that research questions in IPA studies are usually open and broad and there is no attempt to test a hypothesis; instead, IPA is an in-depth exploration of phenomena. The point I wish to make here is that findings from my own research and indeed from other IPA studies are not statistically generalizable- the aim of IPA research is not provide statistically generalizable information. Rather, IPA studies aim to illuminate phenomena and to provide an insight into how participants experience phenomena. In this way, IPA studies aim to

help others understand the phenomena through participants' own accounts. In several other studies that I have read, the researchers themselves also addressed the question of representation and generalisability by noting that their studies are limited to a certain sections of a population that would not necessarily be representative of a wider population and their sample population involves groups of people who might otherwise have been ignored by other studies. I also wish to add as well that in my own research, I have aimed not to be merely descriptive but also to pay attention to the context in which I carried out my research studies including interviews and fieldwork notes and observation.

3.4 Processes of IPA research

Smith and Osborn (2008) provide flexible guidelines for data analysis for IPA studies, which can be adapted by individual researchers to their research. Pietkiewicz and Smith (2014) recommend that these guidelines are only an illustration of different ways of analysing the qualitative material and researchers should be flexible and creative in their thinking and need not take the guidelines Smith and Osborn (2008) have provided as a recipe for data analysis. In general, Smith and Osborn (2008) recommend a step-by-step process, the first of which involves looking for themes from the qualitative data. This means reading and re-reading the interview transcripts until the researcher reaches a degree of familiarity with the data, making notes of themes and significant phrases.

The second stage involves listing all emergent themes and looking for connection between the themes. Some themes are clustered together into superordinate themes (Smith and Osborn 2008); these themes usually correspond to the actual words of the participants and to the raw interview data. The third stage involves organizing and grouping the themes under a number of superordinate theme heading, with each superordinate reflecting the themes clustered under it (Smith and Osborn 2008). In selecting the themes, I was guided by the theoretical framework, namely Bury (1982)'s notion of chronic illness as biographical disruption. I also applied a feminist lens to data analysis. The theoretical concept allowed me to look for and to understand the link between various themes that emerged in the study. The final stage involves continuing the analysis with other themes. Smith and Osborn (2008)

suggest that analysis can either involve a case study on its own or simply a phenomenological approach also incorporate the interviews of different participants together. I discuss the data analysis in more depth in the next chapter of this thesis.

3.4.1 Validity of IPA research

To engage with the debates on the validity and reliability of IPA studies, Smith et al (2009) recommend using Yardley (2000)'s guidelines to assess validity and reliability in IPA studies. Yardley (2000) proposes four key principles to consider when assessing the validity and quality of qualitative research: 1) sensitivity to context; 2) commitment and rigour; 3) transparency and coherence and 4) impact and importance.

With reference to sensitivity to context, Yardley (2000) contends that there is need to consider the socio-cultural context of the study including the area the study takes place, the participants involved in the study and also the relevant theoretical framework and literature. In my own study, I have demonstrated sensitivity to the interview data and to give the participants a voice, I have referred to what they say in their interviews.

In relation to commitment and rigour, Yardley (2000) states that there is a need to engage fully with the topic of the research, to demonstrate methodological competence and commitment to thorough data collection. In my own study, I engaged as much as possible with my research during data analysis and throughout all stages of data collection through fieldwork. Fieldwork took place over the course of approximately one year and included not only interviews but also the research journal that I used during fieldwork. In my own study, I noted that the commitment to rigour is been demonstrated by the number of interview extracts used verbatim in the findings of the research.

By transparency and coherence, Yardley (2000) refers to clarity in communicating descriptions or arguments and ensuring that there is a fit between theory and method. In my research, I have sought as much as possible to be transparent in describing the methods used and detailing the stages of the research process as well as being clear in setting out my findings. I also sought to ensure that the study

fits with the theoretical framework- i.e., my study is about Nigerian women living with HIV and it applies a feminist lens to understand how these women make sense of HIV. Bury (1982)'s notion of chronic illness as biographical disruption provides the theoretical framework for analysing women's experiences of HIV.

Lastly, Yardley (2000) states that the real impact of a study lies in whether or not it adds anything of value to research. The impact of a study can be measured by what it has to say about the topic under investigation. As there are limited studies on Nigerian women living with HIV, my own study would add valuable knowledge to research on women living with HIV in a country in the global South.

3.5 Motivation for using IPA as a research methodology

The aim of my research is to explore the experiences of a group of Nigerian women living with HIV in a city in North-Central Nigeria. I considered other research methodologies including narrative enquiry, grounded theory and action research but I wanted an approach that emphasized the participants' lived experience whilst allowing for the emergence of a deeper and richer data to inform my study of the participants' lived experience of HIV. It is for this reason that I selected a phenomenological approach. IPA is particularly relevant to my study as it recognises the impact of the researcher on the research process, which I felt was important, given my double position as both an insider¹¹ and outsider¹² within the Nigerian context. My goal as a phenomenological researcher is to gain a better understanding of how Nigerian women live with HIV through their accounts of their life with HIV and I wanted to provide data that was full and rich and to be able to interpret the data more deeply.

I am particularly drawn to using IPA as a research methodology because it is a phenomenological approach that has been influenced by the three areas of knowledge that have already been discussed earlier in this chapter (3.2.1). In contrast to other phenomenological methodologies that I explored, I found that IPA

¹¹ As an insider, I was born in Nigeria, lived in child as a child and have Nigerian parents, so I share the same racial origin as the participants.

¹² As an outsider, I am not HIV positive, I am a doctoral student studying at a leading institution in the global North and I have lived outside of Nigeria for most of my life.

retains a focus on interpretation of the participants' interpretation of their experience, 'double hermeneutic', which I felt was quite suited to my study because it aligns with my interest in exploring women's experience of living with HIV from their own perspectives. It also aligns with the feminist lens that I have applied to my study. IPA is particularly useful for carrying out studies in little researched areas and 'one of IPA's strengths is its flexible and inductive approach, which is able to engage with new areas lacking a theoretical pretext' (Dima and Bucuta, 2016:80). In my own study, through IPA, I seek to illuminate the experience of a group of women whose experience of phenomenon remains unknown and misunderstood. I found IPA suitable in enabling me put together the participants' accounts of HIV and through my reflections and analysis, put these different accounts together to create a body of characteristics that represents how the participants themselves understand/interpret their experience.

3.5.1 IPA and the 'hermeneutic circle'

A key attraction for selecting IPA for my research comes from '*double hermeneutic*', my interpretation of how participants interpret their experience. Heidegger introduced the concept of 'hermeneutic circle', which according to Smith et al (2009), is a process whereby individual parts of a lived experience are examined first in parts, then as whole and then again in parts until a level of understanding is reached. I understood that my position as both an insider and outsider had an impact on my interpretation of the participants' accounts of their experience. A feminist lens enhanced my understanding of the participants' experiences by enabling me to consider the impact of power and difference on the research processes, the women's own experiences and how these experiences were represented through my interactions with them as well as with the findings drawn out from my research.

The 'hermeneutic circle' refers to the relationship that exists between the 'part' and the 'whole'- the idea that the part can only be understood as a part of the whole- Smith et al (2009) best illustrates this by stating that the meaning of a single word can only be understood when taken as part of a complete sentence. Smith (2009) illustrates an example of this process in his own study, which reminded me of my own counselling practices: Smith described his own positionality prior to interviews

with his research participants and his own pre-conceptions, which he illustrated on a hermeneutic circle. Once he began his interviews, he took a position that was both open and non-judgemental and together with the participant, they both constructed an account of the participant's account. Once the interview was over, Smith returned to his pre-interview position on the hermeneutic circle where he refers back to his own pre-conceptions, but this time also notes that his encounters with the participant has changed him. Smith (2009) notes that this change continued as he reviewed, questioned and analysed the interview he had with the participant.

IPA is an interpretative process that navigates between different levels and layers of interpretation including one developed by the participant and the layers of interpretations offered by the researcher as a result of their encounter with the participant (Smith et al 2009). Eatough and Smith (2017) states that there are two types of hermeneutics: a hermeneutics of empathy and the hermeneutics of suspicion and they briefly explain the difference between the two- the hermeneutics of empathy assumes an empathic stance and tries to imagine what the experience of phenomena is like for the participant. The hermeneutics of suspicion engages in a process of critical analysis to provide a critical view of experience and probing for meaning in ways a participant might be unwilling or unable to do themselves. IPA researchers engage in both hermeneutics in engaging deeply with the texts of the participants' personal experience (Eatough and Smith 2017).

In line with a feminist approach, I engaged with hermeneutics of empathy through the process of identifying, understanding and empathising with the participants through my reflexive accounts, my field notes and interview transcripts during research analysis. I also engaged in the hermeneutics of suspicion mainly through engaging in providing accounts where the participants themselves questioned how they could have done things differently that might have avoided them contracting HIV- in this way, the participants accounts are not just descriptive and empathetic but also exploratory to their own experience of phenomena.

3.5.2 Bracketing

Bracketing is a key concept of IPA as well as other phenomenological approaches. Bracketing refers to the notion that one can set aside one's preconceptions including

their knowledge or understanding in order to understand the phenomena under investigation. Bracketing draws much of its influence from the writings of Edmund Husserl who was primarily concerned with 'the things themselves.' Smith et al (2009) notes that Husserl believed that reality is created and experienced through conscious acts, and he proposed that researchers should suspend or 'bracket' their 'natural attitude' and be *phenomenological* in order to see phenomena as experienced by the participants themselves. The natural attitudes refers to previously held assumptions or perceptions of what a researcher knows. In practice, bracketing involves a conscious attempt to suspend taken for granted assumptions when investigating a phenomena and the researcher tries to see the world differently while also paying close attention to the participants' views (Finlay 2011). By bracketing, new knowledge emerges (Finlay 2011). This implied that in my own study, I had to disregard any previous knowledge or ideas that I may have had about the phenomena under investigation in order to remain open to exploring and understanding Nigerian women's experience of HIV.

Noon (2018) notes that although bracketing is often reduced to a minority perspective because it is difficult and challenging, it is important to consider bracketing because in line with the nature of phenomenological approaches, bracketing is concerned capturing first person accounts of phenomena. The main challenges for phenomenological researchers are how to facilitate participants' expression of their experiences and how to present these expressions as useful and valid research (Finlay 2011). In my research, this challenge was met in part by bracketing any preconceived notions that I may have had prior to the study so that I remain responsive to the applicants' lived experience of HIV. For me, bracketing was not about being unbiased but an attempt to be opened to new ideas and understandings, particularly as my research was exploratory in nature. I engaged in the process of bracketing through keeping a reflexive journal of my ideas and knowledge, which have been valuable in helping me understand my data and make sense of the participants' experience of living with HIV. Smith et al (2009) suggest that bracketing is similar to researcher reflexivity. Malthouse et al (2014) state that being reflexive involves a researcher being aware of what is going in terms of their own personal thoughts and ability to locate oneself within a structural picture in the research process.

Smith (1996) has contended that researchers adopt a reflexive self, which is flexible and adaptable because phenomena (that is, knowledge or experience) is never static but constantly evolving. Researchers should be able to adapt because a key aim of IPA is not to seek objective understanding but rather, IPA relies on subjective understanding in order to make sense of reality as participants themselves experience it. This is in line with the notion of double hermeneutic. Smith (1996) also suggests that self-reflexivity is a complex process because gaining access to a participant's world may be complicated by language and by the fact that as researchers, we can never hope to gain full access to all of a participant's experience. In carrying out my research, I drew upon my own position in relation to the participants, the phenomena under investigation and my own professional, social and cultural contexts vis a vis the participants. Reflexivity meant engaging in my own presuppositions and in ensuring that I adopted a non-judgemental stance in interactions with participants as well as in understanding and interpreting their experience through the data from their interviews. Reflexivity also helped me in the analysis and interpretation of the data and helped to draw my attention to my limitations. During fieldwork and data analysis, I became aware that it was not possible to gain full access to the *entire* world and understanding of the participants and I could not fully understand *all* of their social reality. I tried to overcome this limitation by engaging in my reflexive self and in this way, opened myself to exploring new possibilities, experience and knowledge. I also applied a feminist lens to reflexivity (see [3.5.3.1](#)).

3.5.3 IPA: a feminist approach, class and decolonising knowledge

A major element of IPA is its focus on participant experience and its emphasis on how they make sense of phenomena. Moreover, IPA includes 'double hermeneutic' which fits in with the feminist approach to this study. IPA enabled me to engage in feminist reflexivity by paying attention to issues of power and gender relations through my own reflexive thoughts and my reflexive observations of the participants' experience through engagement with their interview texts. The goal of feminist research 'is to create spaces and opportunities to reveal lived realities of power inequalities and difference, and provide evidence that can be deployed in working

towards addressing these engrained inequalities. Feminist values are most often deployed to challenge the continued marginalisation of poor women and girls from decision-making, resources and opportunities in a range of contexts. Feminist values and a related focus on 'gender' can also allow us to talk about.....gendered power relations between individuals and groups' (Jenkins et al 2019:415).

A feminist focus on power, gender and inequalities allowed me to identify, scrutinize and challenge underlying assumptions about Nigerian women's experience of living with HIV, particularly with reference to the treatment providers' efforts to promote the concept of 'Living Positively' with HIV. In carrying out my research, I had to consider my own positionality as both an insider and an outsider. As I have previously mentioned in reflexive notes presented in chapter one, I grew up in two parallel worlds- I am a black African woman of Nigerian origin who grew up outside Nigeria, in two countries in the global North- Ireland and the United Kingdom. I am not HIV positive but since childhood, I have lived with a disability that is both visible and invisible- I am a deaf individual who has worked hard to overcome deafness and have experienced bullying, discrimination and stigma on account of profound hearing loss. My own experience of living with hearing loss and of being a hard of hearing black African woman had an impact on my ability to relate better to the participants' accounts of living with HIV.

I also had to consider the impacts of race, class and power, particularly in the context of postcolonial Nigeria. I am a black woman studying in a UK institution where Eurocentric paradigms dominate the curriculum. Concerning class, I am an upper class researcher with Nigerian roots exploring the experience of poor women in Nigeria; lastly, in reference to education, I am a product of western education received from institutions in Ireland and the UK unlike the participants. In terms of the power relations between myself and the participants, I was seen by the participants and the treatment providers as an 'expert' and respected as such, yet I also recognised the power of the participants themselves- without these women, there was no way I would have been able to carry out this research. The reality for me was that these women held the power to enable me carry out this research and the information they provided in their interviews constitutes a powerful stool that contributes to knowledge about their experience of phenomena. My class, education,

knowledge and exposure to the world outside Nigeria has given me power and has placed me in a powerful position vis a vis the participants but equally too, the women themselves held the power to provide the knowledge that enabled me to explore their experience of phenomena.

In line with Jenkins et al (2019), adding a feminist approach to my research strengthened my relationship with the participants by lending a sympathetic approach to their experience of power, poverty and gender inequalities. In addition, a feminist approach added strength to IPA itself, particularly through my reflexive thoughts which paid attention to the issues of power, difference and status that occurred within the relationships that I developed with the participants. Taking a feminist approach through my engagement with 'double hermeneutic' enabled me to empower the participants through my interpretations of the participants' experience of living with HIV. My interpretation enabled me to help participants challenge (even if indirectly) existing social, political and cultural structures that have disempowered them. In taking this approach, I agree with Jenkins et al (2019: 415) that feminist researchers 'are interested in power: its nature, the ways it can be wielded, and by whom.' I am in agreement with Jenkins et al (2019:415) that lending a feminist approach to research is important because it helps 'to achieve gender equality by asserting full and equal rights, is about using agency-'power to' and 'power with'- to challenge patriarchal 'power-over.'

My thinking on using a feminist approach to IPA developed due to the further thoughts I had about the extent to which I could apply a feminist approach to IPA. I had already started thinking along feminist lines, which was apparent from my fieldwork notes although I had initially neglected to draw upon these more explicitly during my analysis because I was navigating through a large amount of interview data and field-notes that initially made it difficult for me to focus on drawing out the feminist perspectives that emerged from the data. In developing a feminist approach further, I refer to Jenkins et al (2019:418) who propose that, 'a critical element of the feminist research process is for feminist researchers to reflect on their own position and location in relation to their research participants, in this case, in the global South. Every writer whose voice is included in this issue considers this question, sharing

their self-reflections on who they are and how their lives have shaped the way they see and understand the world around them.’

A feminist approach is participatory in nature, particularly where it pays attention to issues to power and gender inequality. This is particularly important for women as it ‘opens up the possibility of developing research that responds to and emerges from, the needs of marginalized groups and communities involving them in conceiving and undertaking research that they and their allies can deploy to effect meaningful change on the ground’ (Jenkins et al 2019:418). I found that a feminist approach is not only useful but also appropriate and works well with IPA, as IPA itself is a form of participatory research with its collaborative methods. In my research, I tried to equalize my relationship with each participant by acknowledging that each had the power to bring their knowledge to a wider audience beyond their local community, since it is their knowledge that forms the basis of this research study. It has been through a review of my field notes that I realized how a feminist lens has already enveloped my thinking on my research, my field notes and my relationship with the participants. As I began to think more creatively, I have become more explicit in applying a feminist lens to IPA as I want to contribute to the literature on women living with HIV with specific reference to Nigerian women. I am also particularly keen to lend a feminist approach to IPA because my studies focus on issues that are traditionally considered to be feminist issues such as gender inequality, power and poverty as these are issues that have had an impact on women’s experience of HIV.

A recent study from the global South has applied a feminist approach to IPA. Clifford et al (2019) applied a feminist approach to IPA in a resource-constrained nation to explore Jamaican women’s experience of disclosing their HIV status to their children. They presented ‘three gems’ to illuminate the participants’ lived experiences, utilizing emotion work as a concept to structure the participants’ narratives and to challenge existing policy discourse on maternal HIV disclosure. Applying a feminist approach to IPA enabled the researchers identify the wider contextual factors that influence maternal disclosure such as female sexuality and mothering. Their findings challenged policy recommendations on maternal disclosure of HIV status to their children, finding that maternal disclosure of HIV status to children is difficult and complex. Clifford et al (2019:238) note that lending a ‘feminist approach

complements key elements of IPA including the focus on individual experience and sense-making and the emphasis on interpretation by both researchers and participants.’ They further stated that ‘combining a feminist approach with IPA helps recognise difference and power imbalances and acknowledges the impact of wider structural factors on the research process and on the women’s lived experiences’ (Clifford et al 2019:238).

3.5.3.1 Feminist approach to reflexivity

Lastly, I also applied a feminist lens to reflexivity and in my thinking in fieldwork; taking a feminist approach to issues of power of inequalities enabled me to challenge underlying assumptions that are prevalent in the literature on the black African female experience of HIV. Adding a feminist lens to reflexivity allowed me to situate my position in relation to the participants and the research environment whilst paying attention to issues of power, class, ethnicity and education. Focusing on these issues was particularly helpful in helping me design my research, carry out interviews, analysing my data, writing my field-notes as well as helping me give careful consideration to ethical issues, potential impact of my research and research outcomes.

3.5.3.2 Some philosophical and feminist reflections

The participants and I shared some commonalities in being women who are subjected to socio-cultural bias on the basis of our gender. We share differences too- we are women from different ethnic groups based in central Nigeria, a part of Nigeria politically known as the North-Central. Nevertheless, we overcame our cultural barriers through language and communication by speaking Nigerian pidgin English and communicating in Hausa. Although I am not a fluent Hausa speaker as I have lost fluency in the language, I was still able to communicate some common words in Hausa with participants who could not speak English and also in Nigerian pidgin English. The shared cultural affinity in being women from the North-Central region provided added impetus for me to take a feminist stance. Being an ‘insider’ through a shared cultural affinity enabled me to establish a relationship with each participant that was dynamic, reflective and interactive. I also subscribe to phenomenology since my research is phenomenological in nature and shares a common trait with phenomenological studies in having an idiographic focus.

I am committed to understanding how participants live with HIV. I am interested in interpreting each participants’ experience of HIV through accounts from their interview data. I recognised that I needed these women to share their knowledge so that I could carry out my research. I also recognised the context in which I was

carrying out my research. Nigeria is one of the most difficult places to be a woman in the world- women are subject to harmful cultural practices, there are high poverty rates, women are subject to political exclusion and experience economic inequality and low literacy rates.

At the same time, in recognising that I cannot always operate out of my contexts, i.e., where I come from, my worldviews and preconceptions, I recognised that I am also an outsider and in fact, my position as an outsider became more relevant as the study progressed. I left Nigeria at the age of ten to start secondary school education in Ireland and I have lost the ability to speak Nigerian languages and due to my education, I have western cultural values that are not easily compatible with those of the participants. Finlay (2011) states that people are embedded in their social reality. I recognise that like the participants, I am also embedded in my own social context. I can only begin to make sense of others if I can make sense of my own context- that is, my own cultural, historical, linguistic and social contexts.

I had to become reflexive in interpreting each participant's experience from participants' own perspective, which I considered as critical because the participants are HIV positive and I am not. Reflexivity enabled me to become more conscious of my thoughts and to apply a feminist lens to understand the participants' experiences. I also acknowledge from my experience of working with participants in my research that interpreting the experience of the participants is a complex and time-consuming process that relies to some extent on my judgement and 'insider' knowledge. To minimise errors, I took care when communicating with participants, including returning interview transcripts to participants to reflect on what they had said and to make corrections where possible

Summary

In this chapter, I discussed IPA, my motivation for selecting IPA as a research methodology and described how I applied a feminist lens to my research. I also addressed some of the issues of IPA and noted that IPA has an idiographic focus, which is suitable for exploring the experiences of HIV positive women living in a country in the global south, namely Nigeria. Lending a feminist focus to IPA allowed me to appreciate the contextual factors that affect the lives of Nigerian women. A feminist lens also permeated my fieldwork journal and the reflexive notes that I made at the end of each day during fieldwork. A feminist lens in IPA put women at the centre of my study by emphasising their experiences through their own voices and my interpretation of how they make sense of their experience.

Chapter Four: The research methods

In this chapter, I describe the research methods, data collection and analysis. I also discussed the ethical considerations that guided my research and study limitations. The study used qualitative methods to investigate the experience of a group of Nigerian women living with HIV in Jos, North-Central Nigeria. This chapter sets out the processes through which the research study was carried out.

4.1 Research design

My research is a qualitative study that employed a phenomenological approach, which involved fieldwork observation and semi-structured interviews, to explore Nigerian women living with HIV. A phenomenological approach was selected to elicit detailed information about a little investigated area, specifically focusing on Nigerian women. The semi-structured interviews used open-ended questions that engaged the participants in a conversation that flowed naturally from a set of pre-determined questions, to provide data, to represent as close as possible each participant's own experience. As part of the study's commitment to the idiographic, the interviews were theoretically derived, with the aim of capturing both the 'whole' and 'parts' of HIV positive Nigerian women's lived experience. My research was also theoretically informed in its interpretation. The research was carried out with a relatively large (for IPA) sample of eleven women with a purposive and homogenous sample, in accordance with recommendation from Smith et al (2009) on IPA studies. The data was collected from semi-structured interviews which were individually transcribed verbatim. Additional data was collected from researcher fieldwork observations and in this way, i was able to gain an understanding of the participants' lived experiences. Fieldwork also involved making notes of my observations and reflexive thoughts, which also enabled me to understand the data better during the analysis of the interview data as well as my own positionality during the research process. The study also utilized a flexible thematic analysis that provided an idiographic overview of participants' accounts, enabling the identification of superordinate and subordinate themes which captured the essence of each participant's own account, in accordance with the principles of IPA (Smith et al 2009).

4.2 Research Procedure

4.2.1 Sampling and selection

The research used purposive sampling to recruit participants. Purposive sampling is a technique that involves identifying and selecting individuals with knowledge or experience of the phenomena under investigation (Palinkas et al 2015). In line with Smith et al (2009)'s recommendation, the study adopted a purposive sample based on homogeneity in order to reduce variation and simplify analysis. Smith et al (2009) recommend purposive sampling to achieve a homogenous sample as this involves using only participants who can best inform outcome because of their experiences. The decision to use only females reflects the fact that studies have generally found that more women than men access treatment for HIV (Moshia et al 2013). I also gave due consideration to gender and cultural factors- it would be easier for me as a female to approach and recruit other women and from discussions with Nigerian counsellors who state for cultural reasons, Nigerian men may not be willing to discuss their personal life with females. Smith et al (2009) states that homogeneity is crucial for a better understanding of the experience of the phenomena under investigation. They argue that a heterogeneous sample would be more demanding and analysis more potentially be more complex. It is partly for this reason that participation was limited to women since their experience of living with HIV may be different from that of men. The use of purposive sampling reflects my concerns not only with achieving homogeneity, but also to construct knowledge that writes about women and to explore and challenge prevailing notions of what HIV means for the women in this study who are living with it. Purposive sampling enabled me to decolonise knowledge so that the perspectives of non-Western female subjects could be considered as legitimate knowledge.

4.2.1 Site of Study

The research took place in Jos, North-Central Nigeria. Jos is the capital of Plateau, one of the 36 states and Federal Capital Territory that constitutes the Federal

Republic of Nigeria. Plateau State has a population of 3.2 million people¹³ and Jos is home to an estimated 900,000 people, making it the six largest city in Nigeria. Plateau State has an HIV/AIDS prevalence rate of 2.3%, ranking 19th among the 36 states in Nigeria (NACA January 2016). I selected Jos as the research site due to its proximity to the nation's capital, researcher familiarity with the city as well as easy access to treatment providers. I also took into consideration that Jos is also a major research centre and has a large university that has welcomed researchers from all over the world. Jos also has a large and well developed network of treatment providers that provides access to treatment for PLWH, with many patients coming to Jos from other parts of Nigeria to receive treatment.

4.2.1.1 Settings

The interviews took place in a number of locations including counselling rooms, with prior permission from treatment organisations and counsellors, in participants' homes which are located in all parts of Jos and for one participant, in a park on quiet occasions. Data was also gathered from observations of counselling sessions, support group meetings which were held by treatment providers in their premises, community outreaches organised by treatment providers and through conversations with counsellors in their offices.

4.2.1.2 The organisations and participants

Three organisations participated in the study- two non-governmental organisations and a federal government treatment provider- a more detailed description of the organisation is available in the appendix. Organisations A and B are treatment providers that rely on funding from both the federal government of Nigeria and international donors with one key difference- Treatment provider A receives donations from overseas organisations such as the Bill and Melinda Gates Foundation and Harvard University while Treatment Provider B relies to a large extent on donations from US-based religious organisations. Organisation C is a mission-based organisation that provides testing and referral facilities, often recommending those who test positive to begin treatment at either Provider A or B.

¹³ National Public Commission, 2006 census (note: this was the last official population census carried out in Nigeria)

Organisation C previously provided treatment facilities such as distributing ARVs but had to stop due to limited funding and organisational capabilities. Additional information is provided in the appendix section.

Prior to beginning fieldwork, I obtained approval to carry out my research from the IOE (Institute of Education) Ethics committee and then approached the three service providers that agreed to participate in the study. I applied to each of the organisations for its own ethical approval. I had discussions with counsellors and programme co-ordinators from the three treatment providers and due to issues relating to patient confidentiality, the organisations did not permit me to directly approach female clients- instead, counsellors would meet or contact their clients individually to see whether they would be interested in participating in my study and once they agreed, they would pass on their details to me to contact them directly to arrange meetings to discuss my research further and to seek consent directly.

I provided members of staff with an inclusion and exclusion criteria for recruiting participants from among their patients. Two of the organisations (A and B) approached their clients to inform them of my study. Recruiting participant was a lengthy and complex process but in this way, I was able to meet eight women who eventually agreed to participate in the study, with the understanding that their participation is voluntary and they could withdraw at any time without giving a reason. I agreed with both participants and treatment providers that data from interviews would only be used for the purposes of my research and refusal to participate in the study would not hinder continued access to HIV treatment. I would also not share information from the interviews with counsellors or treatment providers.

At the third organisation (C), the co-ordinator advised that the best way to recruit participants would be through a group meeting with the women who attend the organisation. The group meeting was organised in February 2013 and I was able to discuss my study and the nature of the research with women who attended. I took questions from participants and following extensive discussions, I recruited four women, of whom one eventually dropped out and the data that she provided was not included in the findings of the study.

4.2.1.3 The Sample

Eleven HIV positive Nigerian women living in Jos participated in this study. I interviewed each participant three times, with two of the women interviewed four times. All the participants in the study had been living with HIV for at least one year prior to participating in the study. To provide anonymity and confidentiality, I assigned a pseudonym to each participant. Because counsellors referred the participants for the study, there were some variations between women in terms of age, length of time since their HIV diagnosis, marital status, religion and level of English language proficiency. There is further detailed information about the participants and treatment providers in the appendix section.

4.2.1.4 Inclusion and Exclusion criteria

In recruiting the participants, I paid attention to some inclusion and exclusion criteria. Inclusion criteria refers to the specific characteristics that a person or population must possess and include key features such as gender and age (Patino and Carvalho Ferreira 2018). Exclusion criteria refers to the features that deem a participant as inappropriate for inclusion in the study (Patino and Carvalho Ferreira 2018). In setting the inclusion criteria, I gave due consideration to age, gender and length of time since HIV diagnosis. The main criteria for participation is that the participants had to be HIV positive and female. As already noted elsewhere in this study, there are very few research studies pertaining to HIV positive Nigerian women. Therefore, being HIV positive, female, Nigerian and living in Nigeria is necessary.

Participants had to be aged between 18 and 45 and to live in Jos, due to Nigeria's sheer geographic size. Narrowing the focus population down to women living in Jos minimized the risks for the participants and myself (given Nigeria's poor transport infrastructure as well as reducing stress for the participants themselves). To avoid ethical issues and due to the sensitive nature of the study, females below the age of 18 were excluded from the study, as were pregnant women or females who were diagnosed less than a year prior to the study.

In brief, the inclusion criteria were as follows:

- Participants must be females aged between 18 and 45
- Participants must have been diagnosed with HIV for at least a year
- Participants must be based in Jos, Plateau State
- Participants must be willing to participate in the study and to share their experience of living with HIV
- Participants must be able to communicate in English

The main exclusion criteria was that participants should not have participated in a similar study elsewhere. The aim of this exclusion criterion was to minimize stress on participants. Due to the sensitive nature of this study, women with a history of depression and those below eighteen years of age were not included in the study.

4.3 Data Collection

Prior to carrying out fieldwork, I undertook a review of existing literature on Nigerian women and HIV on online research databases including but not limited to JSTOR, Google scholar, ScienceDirect, Medline, Tandfonline, John Wiley and Wiley-Blackwell. I combined several key words such as 'Nigeria', 'African', 'women', 'HIV, Nigerian women, stigma', 'HIV/AIDS' and 'biographical disruption' but qualitative studies relating to Nigeria women with HIV were generally limited. To overcome this, I also researched the literature on the experiences of HIV positive women in the Western African region but most studies from West African countries are in French rather than English. The scope of the literature review was then expanded to review studies from Southern and Eastern Africa including South Africa, Kenya, Uganda and Zambia.

4.3.1 Semi-structured interviews

The semi-structured interviews that guided my research was based on the relevant literature review, discussions with counsellors at treatment centres and my own thinking which is based on my experience as a counsellor. Semi-structured interviews may consist of key questions that reflects the exploratory nature of the research and are flexible and adaptable to allow the interviewer and interviewees to pursue different ways of exploring the research questions/aims in more depth

(Mason 2018). Smith et al (2009) recommend using semi-structured interviews in IPA studies as this would allow for a more in-depth data. Therefore, my study utilised flexible semi-structured interviews with eleven female participants. I interviewed all participants three times, with two each interviewed on one further occasions.

The semi-structured interviews were consistent with the feminist approach to the study, given the paucity of research studies exploring the experiences of HIV positive Nigerian women. The semi-structured interviews allowed me to understand each women's particular experience of HIV, which also reflects my commitment to idiography, or to the particularity of Nigerian women's experience of living with HIV. I found semi-structured interviews useful because it enabled me to make some epistemological assumptions about myself as a researcher and about the women who participated in the research. A key advantage with semi-structured interviews was the freedom and control it gave participants because conversations followed a natural path during the interviews.

These interviews provided the basis for data collection and reflected the idiographic nature of my research because of its focus on the subjective accounts of each participant. Semi-structured interviews also reflected both my ontological and epistemological positions- first, I see the women as important actors who construct their own experience according to how they live it and secondly, these women's accounts are open to my own interpretation of what I understand of how they experience their lived experience. I used an interview guide to address the main aims and questions of the study.

4.3.1.1 The Interview guide

Smith et al (2009) state that interview guides should only be use as a guide and interviews should be guided by what the participants say rather than by the researcher. I modified and adjusted it, where necessary, to ask probing questions that often elicited a rich response from the participants. The interview guide was flexible, exploratory and allowed me to ask question that reflect both the phenomenological and idiographic nature of my study. It allowed for the emergent of

relevant information that informed my study. A copy of the interview guide is provided in the appendix section (General discussion guidelines: appendix 4).

The interview guide had two key aims:

- a) To obtain background information about the participants and this provided a useful starting point for the subsequent conversations
- b) In line with the aims of the study, to obtain specific information about the participants' experience of living with HIV and what it means for them.

In my research, interviews generally followed a flexible format with open-ended questions that were exploratory in nature. Adopting a flexible approach during the conversations empowered the participants by giving them a voice and helped to minimise the power hierarchy between the participants and myself. The exploratory and flexible nature of the interview guide meant that I could ask questions that would facilitate dialogue between the participants and myself and encourage them to speak freely of their experience.

These interviews varied from twenty minutes to one hour. Interviews for the participants who were recruited from Organisation A took place in the counselling rooms provided by the counsellors and for these participants, interviews took place when the women came to collect their medication- the sole exception of this was Binta, as she was not yet on medication; she insisted on meeting in a park in the afternoon for the interviews, as parks usually very quiet at this time of the day. For the participants from Organisation B, we used a variety of locations including the counselling rooms at either Organisations A or B (as some clients from B often attend A to participate in support group meetings or workshops, for which the counsellors at either organisations gave permission when the counselling rooms were not in use and following prior notice), with one participant from organisation B opting to have the interviews in her own home, as she lived alone and could not afford the transport fare to the interview site. This participant refused to accept my offer to pay her transport fare. Two participants from Organisation C were interviewed in neutral locations of their choosing- Rabi's interviews, for example took place under a tree shade close to a church where we were not disturbed.

The first conversations focused on building relations between the participants and myself as well as providing an important set up for the second sets of interviews. The women spoke about the circumstances that led to their diagnosis. The second set of interviews reflected further back on their stories by focusing on life in the aftermath of HIV and the third and final interviews provided an opportunity for reflecting on our relationships, reviewing previous conversations and process of debriefing with a view to terminating the interview process.

4.3.1.2 Pilot Interviews

Pilot interviews were trialled prior to the interviews with the participants. Leon et al (2011: 626) state that, 'the purpose of conducting a pilot study is to examine the feasibility of an approach that is intended to be used in a large scale study.' Prior to interviewing the women who participated in the study, I carried out two interviews, each with different HIV positive women. The aims of the pilot interviews were to try out my interview techniques, test the questions I had set out in the interview schedule to ensure that these were appropriate and easily understood and to familiarise myself with my research and interview methods. I also wanted to familiarise myself with carrying out data analysis as well as develop the steps needed in seeking and obtaining consent during fieldwork. The pilot interviews enabled me to reflect on my listening and observation skills and introduced me to note taking techniques.

Through these interviews, I was able to identify issues with some of the questions and where necessary, amended or eliminated these questions. The pilot interviews also highlighted the difficulty that I would have in recruiting participants- it was difficult to meet HIV positive women who agreed to take part in the pilot interviews and there are issues relating to privacy and confidentiality- treatment providers were reluctant to permit me to approach their clients directly. I resolved the issue of recruiting participants by providing counsellors with a list criteria in approaching potential participants and informing them of my research study. Just as importantly, through these pilot interviews, I came to understand that transcribing interviews and analysing the data would be both intensive and time consuming. The pilot interviews also made me aware of the need to consider socio-cultural contexts of the participants and to pay attention to issues of power hierarchy that might arise. A

valuable lesson that I learnt from the pilot studies was as HIV is a stigmatized condition in Nigeria and there is sensitivity surrounding HIV research. I would therefore need to be sensitive to the needs of the participants, to build trust and to establish rapport with the participants and the organisations participating in the study and to be careful with the questions that I was asking. I also understood that women could refuse to answer questions and that it is their right to do so.

Reflexive thought on interview guide

The interview guide partly reflected what I had read in the literature and my own thoughts about what I wanted to explore. As the aim of my study is to explore how Nigerian women live with HIV, I spoke with the participants at length about their life with HIV, its impact on their life and their coping mechanisms. To this end, my own contexts played an important role in the emerging data, given my interpretivist stance but I took care to avoid revealing the emotional impact some of these stories had on me. In listening to the stories that the women construct around HIV, I became conscious of a shift in power dynamics during interviews. The women had the power to tell their stories in terms of what they say, how they tell it and what to include or exclude from their stories- I had no control over this. The participants controlled their stories and my role was to listen to these stories and try to make sense of these stories from the participants' own perspectives and where possible, to prompt these stories through the questions that I ask.

I understood from my observations in the fieldwork that gender and power dynamics needed to be considered and I saw how these influenced the way I approached my research. It is for this reason that I decided to interview women who were unknown to me and in this way, I would be able to 'bracket off' any previously held assumptions about women that I do not know either personally or professionally. To overcome power dynamics, I offered the participants the choice of selecting venues for interviews and the times and dates for these interviews. I was also conscious that most of the participants were not as privileged as I have been.

4.3.2 Field notes

During fieldwork, I kept a notebook where I recorded meetings, observations and my reflexive thoughts, which have been useful in guiding my data analysis. The field notes are quite detailed and were useful in helping me remember details of particular events/actions from the field and they helped me to maintain a record of my research as it unfolded over time. Philippi and Lauderdale (2017:2) suggest that field notes are useful in 'constructing thick, rich descriptions of the study context, encounter, interview, focus group and document's valuable contextual data.' I found that my field notes enhanced my data and provided a rich context for analysis; the field notes

helped to frame my study in a time and a place and I took care in ensuring that information on participants themselves have been de-identified- for example, using pseudonym in place of their real names. Friedemann et al (2011) suggest that the use of field notes with reflective entries is an important tool to explore a researcher's level of subjectivity, thereby minimizing researcher bias and enhancing the validity of findings from a research study.

4.4 Data Analysis

Data analysis is a process of bringing order and meaning to the data that emerges from a study. I carried out thirty-five interviews and interviewed all eleven participants three times, with a fourth interview for two participants, as these had to be broken into separate sessions. The interviews took place over the course of one year, with each interview audiotaped; I sought consent for recording interviews on an ongoing basis prior to each interview. The analysis of the data generally followed the guidelines of IPA as recommend by Smith et al (2009) although they also recommended that these guidelines be intended as a guide only, which can be adapted as appropriate by researchers. Smith et al (2009) recommended an analytic process in IPA, which involves engagement with the text until a closure is achieved. The steps involved in IPA data analysis are as follows:

1. The detailed examination of a transcript until a degree of 'closure' with the transcript is reached. Closure is achieved by reading a text until it is understood.
2. This step is followed by repeating the same process with all the transcripts until 'closure' is reached for each transcript
3. Once the transcripts have been read, the researcher carries out analysis across the interviews and a table of themes emerges from each interview so that recurrent themes can be identified across cases and a sketch of these recurrent themes are generated for the groups and the findings are written on the basis of the theme.

The interviews provided a rich and detailed account of each participant's experience of living with HIV. I first began by transcribing all interviews verbatim. I then began

data analysis by engaging with the text and in doing so, I engaged in the process of double hermeneutic as I seek to interpret the data and try to make sense of the data through the participants' eyes. Transcribing and engaging with the text took approximately six months of intensive listening and re-listening to the taped interviews.

4.4.1 Selecting and clustering themes

As I had collected so much data, I had to devise a method for organising the data to facilitate easier engagement with the text. I undertook data analysis in two stages. For the first stage, all interviews were sorted into piles- first, second, third and fourth interviews. I read and reread the interviews, in keeping with the idiographic nature of IPA, which calls for researchers to engage in-depth with the text until they achieve closure with the data. For each pile, I pasted a paper on a wall and jotted down themes once I had engaged with each interview transcript, a process that I repeated with all interviews. Once I had noted down as many themes as I could, I looked at these themes together on a large piece of paper. In picking out themes, I was guided further by the three elements of Bury (1982)'s theory of biography disruption. This enabled me to narrow the focus of the findings to selected transcripts and to follow Smith et al (2009)'s recommendation for the systematic analysis of the data. I repeated the same process with all interview piles.

For the second stage, I reread selected interviews, making notes on the right hand columns of each interviews that connected with selected themes. The transcripts were reread again in a systematic way with the identified themes noted on the left hand column of each interview transcript. I highlighted themes that I thought would conceptualize the experiences of the participants and capture meanings that were reflective of these experiences and of biographical disruption as noted by Bury (1982). The next stage in this second stage involved clustering the themes. In clustering these themes, I engaged in double hermeneutic by moving back and forth between the themes that I had identified from the participants' text that conveyed meaning. By engaging in double hermeneutic, I was able to picture myself in each participant's shoes to gain further insight into their thoughts, their emotions and their body language. Re-listening to the taped interviews was particularly useful in this

process. The notes that I took during interviews in Nigeria were also helpful in data analysis. I took care to ensure that the selected themes reflected participants' own accounts of their experiences rather than my own expectations, though Willig (2008) has argued that a researcher's interests and contexts will inevitably have some impact on their interpretation of the data.

Once I had clustered the themes, I tried to ensure that these themes connected and there is a relationship both between and within the themes and subthemes, in accordance with the principles of IPA (Smith et al 2009). The selected themes reflected commitment to idiographic accounts of participants' own unique experiences and these in turn led to the identification of superordinate themes which linked each individual accounts- in this way, three superordinate themes were identified and are discussed in the next chapter. Clustering the data reflects my concern with the particular, that is, my commitment to understanding each participant in relation to themselves and to other participants in the study. Ultimately, in data analysis, my aim was to convey meaning as seen through the participants' own lens. In this way, I was able to maintain some connection between both the participants' voices and the overarching aim of my research.

4.4.2 Themes Identified

Smith et al (2009) have noted that it can be difficult to add, reduce or prioritise data in setting out the themes; in my own study, as so many themes had been identified, I selected themes based on their prevalence, the richness of the specific theme and also as a commitment to the idiographic nature of the each participant's account, I also based selection of themes how each theme can illuminate individual accounts within specific superordinate themes. I also paid attention to theoretical considerations and applied a feminist lens to selecting themes.

The themes that I identified that clustered and connected with other themes in the study are as follows:

Tears (diagnosis, feeling alone)- Testing positive	Shock/Shame (at one self because of HIV)-Testing positive	Sad (diagnosis, thinking of present, past and future)- Testing positive, impact and meaning	Painful (living with HIV)- impact and meaning
Crying/Cried (diagnosis with HIV, living with HIV)- Testing Positive	Sick (diagnosis with HIV, state of health before and after HIV)- Testing Positive	Hope (for the future)- Moving on	Stand/standing (living with HIV)- impact and meaning
Denial (of diagnosis)- impact and meaning	God (spiritual, strength, belief)- moving on	Support (family, relationship)- Living with HIV, Moving on	Courage (facing HIV status)- impact and meaning
Faith (Muslim/Christian)- Moving on	'Normal' life (living with HIV, normality)- Living with HIV, Moving on	Fear of Self- Testing Positive	I am a woman (moving on with HIV, relationship to men and society, gender)- Living with HIV
Running away (from oneself and others running from HIV positive woman)- Living with HIV	Feeling bad (because of HIV, poverty, thinking of one's status) – impact and meaning	Abandoned (relationship- spouse, friends, relatives)- impact and meaning	Stigma (from others)- impact and meaning
Help myself (moving on with HIV)	Death (loss of self, loss of loved ones)- impact and meaning	Accept (living with HIV)- Moving on	'Normal' person (HIV positive woman in relation to others)- impact and meaning
Future (moving on)	Married/get married- Living with HIV & Moving on	Struggles (medication, life, financial, psychological)- Moving on	Education (moving on, going back to school)- Moving on
Guilt (because of HIV status, not fulfilling life goals as a woman)- impact and meaning	Anger (at self, spouses, relatives)- impact and meaning	Medication/medicine (ARV)- moving on	Concern for others (motherhood, protecting others from HIV)- moving on

Reflexive thought on data analysis

Transcribing the data was a long and difficult process. Due to my hearing difficulty, I had to transcribe each interview verbatim and listened to the taped interviews several times to ensure accuracy. Listening to the tapes and reading the interview transcripts was emotionally challenging and at times, I became very emotional listening to these women's voices. At the same time, I had to be careful not to allow my emotions guide my data analysis.

Although I could have used a software to analyse the data, I felt uncomfortable about using software, as I wanted to maintain control over the emerging themes. I also felt that using software would cause me to lose focus with my data, even though

I understand that manually analysing data is complex and time consuming. Manual transcribing of the data allowed me to keep with the idiographic nature of IPA by engaging as fully as possible with the data and I was able to engage in a double hermeneutic process by interpreting the data and seeing things from participants' perspectives.

It was initially difficult for me to approach the data that resulted from the interviews in a systematic way because I had not expected the interviews to produce so much data and I had to resist the temptation to rush through reading the interviews. I read one interview transcript at a time, took breaks between reading each transcript until I became familiar with the text- this was the only way I could do full justice to the accounts of the participants as I was concerned with adhering to my idiographic commitment to them. Although I identified the main themes in line with the literature on biographical disruption, my main concern was to understand the particular, or as Husserl states, 'the things themselves.' Each participant experienced the same phenomenon in different ways and in selecting the themes and subthemes, I wanted to highlight this in addressing the idiographic nature of research.

4.5 Ethical considerations

A code of ethics set out key principles, which guided how I carried out my research, namely my professional responsibility to safeguard the interests of the participants involved in the study, managing my relationships with participants and a commitment to integrity.

My primary responsibility as a researcher is to ensure participant safety. The codes of ethic set out key principles that guided the research process, namely the following:

1. My professional responsibility to safeguard the interests of the participants involved in the study, including seeking and obtaining clearance for audio-visual equipment at all stage of the research.
2. Managing my relationship with all participants, including ensuring that participation is voluntary, seeking consent on an ongoing basis and the participants are not harmed by their participation in the research.
3. A commitment to integrity- ensuring that participants are not offered financial inducement to participate and being honest with the participants at all stage of the research process.

4.5.1 Ethical approval

Ethical approval was granted by the Ethical Policy of the Institute of Education which expects all research conducted by students to abide by the codes of conduct set out on its webpage: <https://www.ucl.ac.uk/ioe/research/research-ethics-ucl-institute-education>.

In carrying out fieldwork, my research complied with guidelines from the British Sociological Association's *Statement of Ethical Practice (updated 2017)*¹⁴, particularly in relation to researcher's professional integrity, conducting research, relationships with research participants, informed consent and ethical guidelines relating to research with vulnerable people and groups. Once the ethical committee at IOE granted ethical approval, I was able to apply for and receive ethical clearance from each of the three treatment providers that participated in the study. Ethical approval from each of these organisations took approximately six to eight weeks before fieldwork began.

Reflexive thought on ethical consideration

In Nigeria, I encountered some issues that I had not anticipated. The first relates to recruiting participants for my research. The ethic committees of two organisations were reluctant to grant permission for me to recruit participants until I clarified that I would not be approaching participants directly but would do so through counsellors who would refer them to me. The organisations were concerned to protect the identity and privacy of their service users and were not prepared to permit me to meet participants directly unless they received permission from their clients first. I provided an inclusion and exclusion criteria to the counsellors to approach potential participants but they did not always stick to the criteria. For example, one of the counsellors selected a woman who received her HIV diagnosis a month earlier until I explained that her recent diagnosis meant that she was likely still dealing with her diagnosis and taking part in my study would probably be too stressful for her. The university's ethical guidelines seemed to imply that it is a researcher's responsibility to recruit participants but in Nigeria, I had to rely on the organisations to approach potential participants first; only then would I be able to meet with the participants to explain about my research and then seek consent. As it had been hard and time consuming work for counsellors to approach participants, I felt that I had no choice than to accept the women they had referred to me, even if they didn't always stick to the criteria- for example, I met Maimuna through counsellor referral- Maimuna is not fluent in English but I was aware of how hard it was for counsellors to approach and refer women like Maimuna, I decided to meet with her, discuss my study with her

¹⁴ Guidelines on Ethical Research, <https://www.britisoc.co.uk/ethics>

and seek consent for her participation and we communicated in Nigerian pidgin English. Selecting participants via counsellor referral might not be the best way to recruit participants but I was left with no option to do recruit participants via counsellor referral, as organisations refused to permit me to recruit participants directly.

4.5.2 Informed Consent and right to withdraw

Research with women can be fraught with ethical dilemmas, some of which involves informed consent and potential harm. A key principle of all research studies is that researchers must obtain informed consent before carrying out their research. Marshall and Batten (2004) have argued that informed consent is a dimension of power and requires informing participants about the study and ensuring that they understand what they are agreeing to do. They state there is a need consider cultural factors when seeking informed consent. Hofstede (1991) and Honan et al (2012) have noted that individuals living in collectivist societies tend to lack individual autonomy yet western institutions have issued guidelines, which are rooted in the individualistic outlook of western culture that assumes universal applicability to cross-cultural research studies. I took into consideration cultural factors with regard to informed consent.

Counsellors working in the treatment centres used the inclusion and exclusion criteria that I had provided to refer selected participants to me, so I had to consider the power dynamics that may exist between the participants and their treatment providers. In a society with paternalistic tendencies like Nigeria where women are socially vulnerable in the conduct of research, I took specific care with regard to informed consent, in line with the World Health Organisation (2016)'s guidelines, which states that in research studies where organisations have granted permission for studies, a researcher must still obtain informed consent from the participants. I took additional steps to meet each selected participant on an individual basis to explain about my research, the nature of the research and to ensure that the women understood they would be taking part in a research study whose findings would form the basis of a PhD thesis.

Two other concerns emerged in relation to recruiting participants through counsellors- the first related to whether information from the participants' interviews

might be fed back to their counsellors- I addressed this concern by advising both counsellors and participants that I would not be reporting data from the interviews to the counsellors. The other issue was the question of voluntary participation in which the participants might feel compelled to participate in the study. I addressed this by informing the participants that their participation is entirely voluntary and has no impact on their ability to access treatment. I also reminded participants of the voluntary nature of their participation during interviews and they do not have to answer questions that they were uncomfortable with. As the participants are women living with a stigmatised condition, I was keen for their voice to be heard but only if they were themselves willing to share that information and had not been forced to participate in my research.

Nine of the participants read the consent form themselves and I encouraged them to ask questions or seek further clarification if there was something that they did not understand. I informed participants of the duration of my research and that interviews would be taped. I informed all the women of their right to withdraw at any time without providing a reason and also informed them that they had the right to refuse consent for taped interviews. I informed participants that whilst interviews would be taped, identifying information would be anonymised. Once the participants had read and understood the consent form, they signed it with the understanding that their agreement was not legally binding and they could withdraw at any stage of the research process. Two of the women in the research are not literate, so I read the consent form and explained each line to them in Pidgin English and encouraged them to ask for further clarification. Once they were satisfied, they agreed to take part in the study and signed the form.

In accordance with IOE guidelines, once consent was obtained, I also provided each participants with my contact details as well as those of my principal supervisor should they wish to raise any concerns about my research study or conduct- contact information included the name, email address and postal address of my principal supervisor.

Reflexive thought on informed consent

I faced some challenges in seeking informed consent for two participants. As part of seeking informed consent, I had to consider the notion of patriarchy- seeking informed consent with Nigerian women may involve also seeking consent from key individuals in the participant's life such as spouses, fathers, uncles or other male relatives. One participant insisted on discussing with her husband first and then asked me to inform her husband. Her husband questioned me at length about my research and the sort of questions I would be asking. Once he was satisfied, he gave verbal consent before his wife agreed to participate and signed the consent form. I did this with the understanding that I would not be interviewing her in the family home or involving any other family member and any interactions would be restricted to the clinic where this participant was receiving her treatment. I met each participant on an individual basis to explain about my study and to seek her consent before I could start interviews. As two of these women neither literate nor fluent English speakers, I took additional steps to explain about my study by communicating in Nigerian Pidgin English. Obtaining informed consent was a long and complex process and I had to consider individual contexts in seeking informed consent.

4.5.3 Confidentiality

Confidentiality refers to 'separating or modifying any personal, identifying information provided by participants from the data' (Coffelt 2018:228). The guidelines from the BSA stipulates that researchers should ensure that participants understand how far they will be offered confidentiality and that researchers should be careful not to give unrealistic guarantees of confidentiality and should not provide information from research to audiences other than those to which the participants have agreed.

I informed participants verbally as well as on the consent form that I could not guarantee confidentiality as the data from their interviews would form the basis of a doctoral study that would be read by others. Nevertheless, information would be de-identified as much as possible. Following agreement with the participants, I assigned a pseudonym to each woman on both interviews and audio recording as well as on field notes. During fieldwork, I kept data from the interviews (both taped and field notes) in a locked drawer in my bedroom, which I kept locked at all times and I was the only individual with access to my data. I kept identifying information separately in a notebook that I could refer and I was the only individual with access to this notebook. I ensured that personal information such as telephone numbers and

addresses were not written in the field notes, to de-identify information as much as possible.

4.5.4 Potential Distress

I was aware that participating in my research could be potentially distressing for some participants. I addressed this by warning participants in advance prior to interview of the questions that I would ask as part of the interviews. I emphasized that some of these questions might be potentially distressing, for example, asking them to describe their HIV tests. I informed participants about the nature of the questions I would be asking prior to interviews on an ongoing basis. I also advised participants that they were not obliged to answer these questions and they had the right to terminate interviews at any stage. I also reminded participants that refusal to participate in or withdrawing from this study later on would not have any negative impact on their treatment.

Where possible, I took steps to minimize discomfort such as stopping interviews, giving participants a break and then seeking consent to either continue with or stop the interviews. During interviews, I also paid attention to signs of discomfort and was prepared to terminate interviews if necessary. One participant cried during her last interview; I stopped the interview, gave her space to cry and compose herself. She insisted on continuing with the interview. After the interview, I provided her with contact details for her to access further psychological support from a clinical psychologist who agreed to offer her service free of charge. I also reminded participants of their right not to answer questions and to withdraw from the study without providing a reason.

4.5.5 Payments and Incentives

As poverty is widespread in Nigeria, it has some important implications for carrying out research studies. Chapter two ([2.4.2](#)) of this research study has already noted that Nigeria women are particularly vulnerable to poverty, with about 70% of Nigerian women living on less than \$1 a day. Poverty may be especially amplified for HIV positive women. The issue of poverty was one I had to be sensitive to, particularly with regard to financial incentives and ethical considerations around this. I informed

participants that I would not be paying them for participating although I would reimburse them for transport fares and provide with food and soft drinks during the interviews. With agreement from counsellors, each participant received a small cotton bag containing a diary with some pens and colouring pencils, a bar of soap and a small piece of cloth at the end of the final interviews as a token of my appreciation.

Reflexive thought on payment and incentives

The issue of remuneration was difficult to avoid in the face of widespread poverty, particularly for women who are struggling to make ends meet. In carrying out my study however, I have to avoid the potential for undue influence, so I clarified during meetings with participants that they would not receive payment for participating in my research although I would reimburse travel expenses for attending pre-arranged interviews. I was also mindful of ethical guidelines regarding financial inducements for participants.

4.6 Limitations of my research

I hope that the information that I have provided in my research could form the basis for further studies on Nigerian women living with HIV. I am aware that as a methodology, IPA is idiographic in nature, given its focus on the particular so the findings of my research cannot be generalized to the broader experiences of HIV positive Nigerian women outside of the study. Moreover, the findings of my research are based on my own interpretation of how the participants interpret their own experiences. I understand that other researchers might interpret the data differently although I have made every effort to ensure accuracy and transparency in the data analysis.

I paid some attention to language (both verbal and non-verbal) and some important issues need highlighting here, including the fact that not all participants were able to express themselves in English, a language that may be their second or even third language. I am unable to speak any Nigerian language fluently which may have had an impact on my interviewing skills and there were some participants who could not always understand my Nigerian pidgin English because I spoke with a non-Nigerian accent- this was the case for some of the women, for whom I had to adjust my

communication style. Language may have had an impact during interviews.

Due to concerns about patient confidentiality, I had to rely on treatment providers to refer participants to my research, so there is a possibility that the counsellors may have selected participants for whom they felt participating in my research might be a way of coming to terms with HIV, despite the inclusion and exclusion criteria that I had provided. The sample comprised women from Northern Nigeria, specifically from the region known as the Middle Belt (or North-Central Nigeria), so the sample may not be representative of the experiences of women across wider parts of Northern Nigeria. As only women formed the basis for the study, their experiences cannot be applicable to Nigeria men who are also a group unrepresented in research studies. Moreover, as my research has drawn much of its data from women who for the most part can communicate in English to a good degree, there is a possibility that if participants had the opportunity to communicate in their own native languages, the data yielded from the interviews might be richer still.

During fieldwork and data analysis, I had to rely on my own judgment to make decisions, including being mindful of my role as a researcher, keeping focus on my research during interactions with the participants and being aware of my own contexts relative to the participants. It was not always easy to be objective and to bracket off some of my previously held assumptions. I was aware of the power relations between the participants and myself. I saw the participants as experts in constructing their own stories and myself as the facilitator on making these stories known to others but in reality, social status may have been a factor in my interactions with participants, something that is also reflective of Nigerian society as a whole.

Nigeria is an unequal society with extreme wealth gap between the rich and poor and women are most affected by this wealth gap- as a result, they are less likely to have access to necessities like food, education, clear water and access to good healthcare. They are also less likely to have access power. In Nigeria, social status based on class, religion and level of education plays an important role in how people interact with each other. The fact that I come from an upper class family, speak English as my first language (a language imposed by colonial rule), educated to third level and I am not HIV positive may have had an impact on the research and

analysis of the data. These limitations however do not take away the fact that my research is an important study that provides an insight into the ways in which Nigerian women live with HIV.

Summary

In this chapter, I have provided an overview of the processes involved in carrying out my study, namely ethical considerations which guided the process, recruiting participants, the use of purposive sampling and the method of data collection and analysis. I have also incorporated reflexive notes that outline the reflections I had during fieldwork.

Chapter Five: Findings

Overview

This chapter together with chapters six and seven provides sets out the findings that emerged from the present research which explored the experiences of eleven HIV positive living in Jos, North-Central Nigeria.

NAME OF PARTICIPANTS	CHARACTERISTICS
Ria	Christian, widow and diagnosed in 2002, works as a counsellor
Halimatu	Muslim, widowed and remarried, diagnosed in 2003, currently studying for national diploma
Irene	Christian, divorced and diagnosed in 2003, has a full-time job
Maimuna	widowed and diagnosed in 2003, is self employed
Cher	Christian, married, diagnosed in 2004, holds a BA but presently unemployed
Rabi	Muslim, widowed and diagnosed in 2006. Self-employed, has never disclosed
Vickie	Christian, Diagnosed aged 17, 2007. Has never progressed beyond junior secondary education
Grace	AIDS orphan, tested positive in 2007. Works as a domestic staff for a large organisation
Talatu	Muslim housewife, diagnosed in 2009 with discordant partner and infected child
Pamela	Christian, tested positive in 2011
Binta	Muslim, divorced/widowed, tested positive in 2012

5.1 Table of super-ordinate themes and emergent themes

Super-ordinate Theme	Emergent Theme
1. Testing Positive	<ul style="list-style-type: none"> I wept, I wept, I wept, I couldn't walk from that office - Ria
	<ul style="list-style-type: none"> I felt bad from the beginning because I wasn't expecting it- Halimatu
	<ul style="list-style-type: none"> Deep within my spirit, I am coming to God that I don't have it- Irene
	<ul style="list-style-type: none"> I didn't find it easy, I'm thinking that it is the end of the world- Grace
	<ul style="list-style-type: none"> I cry, I no dey eat food, even sleep, I no sleep- Talatu
	<ul style="list-style-type: none"> I felt the ground should open up and close me up. I felt like screaming- Pamela
2. Living with HIV	<ul style="list-style-type: none"> In fact, honestly, it wasn't easy for one to be positive- Cher
	<ul style="list-style-type: none"> I prepared my mind that what will be will be- Rabi
	<ul style="list-style-type: none"> It is a raw experience- Vickie
	<ul style="list-style-type: none"> You have the fear of going into a relationship- Pamela
	<ul style="list-style-type: none"> At times, I feel guilty- Irene
	<ul style="list-style-type: none"> Will I get a husband again? Can I have another child?- Binta
	<ul style="list-style-type: none"> I just want to end it, that made me decide to kill myself- Grace
3. Disrupted Lives, 'Repaired' Biographies	<ul style="list-style-type: none"> The way I was before is not the way I am now- Ria
	<ul style="list-style-type: none"> I say nothing, I will thank God for my life, that's what I told them- Maimuna
	<ul style="list-style-type: none"> From that time, I can open up- Vickie
	<ul style="list-style-type: none"> HIV is a blessing to me- Halimatu
	<ul style="list-style-type: none"> I have zeroed my mind to towards this illness- Binta
	<ul style="list-style-type: none"> After all, it's not being written on my face- Irene

5.2 Theme One: Testing Positive

Overview

This overarching theme came from my attempts to understand the participants' experience of receiving a diagnosis for an illness that they would have to live with for the rest of their lives. In this theme, participants discussed their experiences of taking an HIV test, the reasons for taking the test and the shattering blow of receiving a positive HIV test result. They spoke about their emotional reactions to their test results and their life in the aftermath of their diagnosis with HIV.

5.2.1 'I wept, I wept, I wept, I couldn't walk from that office'- Ria

Ria has vivid memories of learning for the first time that she is HIV positive. She endured a difficult pregnancy and had experienced bleeding,

'I was seven months pregnant, I had started bleeding. I confirmed to them in the clinic.'

Ria had some lab tests as part of her antenatal programme including an HIV test but she remembers that her doctors never informed her properly of the nature of the tests,

'they gave me a list to go and do the same morning, including HIV. They didn't tell me the tests I should go do. They just sent me to the lab.'

At the time Ria was tested in 2002, the procedure for collecting tests then was for patients to bring their own results to the doctors who then read the results before informing their patients of their test results, which reflected the nature of the power relations between patients and hospitals. Even as late as 2013, hospitals were still running tests on pregnant women with neither their knowledge nor consent, similar to the experience of the woman described in chapter [1.1.1](#) of this thesis. Ria, in common with many patients at the time, did not question this. For many women, pregnancy is often the first time they receive an HIV diagnosis. Ria remembered the

secrecy of the tests she was asked to take and the doctor's action,

'they gave us the results, the HIV test. The HIV test is normally clipped. They don't give you opened. They clipped HIV test then if positive or negative...when they gave me the result, it was clipped. The doctor saw the way I was, with my pregnancy and it was so big. I don't know, he didn't disclose the status for me, he told me that I should go behind the building because there is an office behind the antenatal.'

Ria was given her results in a sealed envelope and asked take them to her doctor; it did not occur to her to check the results herself and she didn't understand the seriousness of her situation. The doctor's dilemma was how to inform her of the results in the light of her pregnancy which he resolved by sending her to another building within the hospital complex. Ria had assumed that everything well when she arrived at the building the doctor had referred her to and she saw posters about HIV on the wall, she was confused by this,

'I was just jubilating my result thinking everything was fine...till they called me, I don't know what is the contents of the paper, so I took it to the office. When entering that office, I saw posters of HIV, my mind did... since I can read and write, when I saw that poster, I felt somehow within the bottom of my heart, the results, I had not opened it o. I entered the office, they welcomed me... collected the form...the counsellor....'

Ria remembers seeing more posters about HIV in the counsellor's office and she stated that, *'I felt somehow within the bottom of my heart'*, suggesting that she had a terrible premonition about what was about to happen.

Ria remembers the unexpectedness of being told that she is HIV positive and how bewildered she was by the counselling she received. Her counsellor began preparing her for her results by drawing upon her spiritual beliefs,

'she welcomed me as somebody she know for long. She now asked me, 'am I a Christian?', I say 'yes.' Am I a church member? I say 'yes.' Did I know that Christ died because of me to give me life? I say 'yes.' She say if I happen to die today, did I believe that...where would I go? I say I would go to heaven...do you believe that you would see Jesus Christ? I say 'yes, I will see Jesus Christ. That is my heart's desire.' She now asked me, have I been hearing about HIV? I say yes, I have been hearing about HIV. Do you know what HIV is? HIV is a virus. She asked me, do I believe am I going to die if

they find you with HIV, I say yes, why not?... she now stood up and rubbed my back, 'madam, take it easy, it is a normal thing'... when she told me that I am HIV positive, I couldn't hold myself....'

The counsellor mentioned the word 'die' in her introductory talk with Ria in an effort to be helpful but it is something that has remained stuck in Ria's memory- it gave Ria the impression that she would soon die. Ria was shocked when she was told that she is HIV positive- she had not expected it and wept uncontrollably,

'I was unable to walk out of that office down to my house....my pregnancy was 8 months, I was confused...I was weak... I wept, I wept, I wept, I couldn't walk from that office... they didn't tell me. You know they were doing it silently [HIV test]....'

There was a sense of powerlessness, loneliness and disbelief at receiving a positive diagnosis. Ria focused on the fact that she was never given a choice on taking an HIV test but her answer to the question that her counsellor asked her about her knowledge of HIV suggests that she would probably not have given her consent to a test if she had been offered one because she thought HIV meant death,

'do I believe am I going to die if they find you with HIV, I say yes, why not?'

Ria tested positive for HIV at a time when much of the discourse around HIV focused on it as a sexually transmitted disease which ends in death and Ria herself thought that HIV was a death sentence. She was particularly distressed by the secrecy surrounding her test as being tested without her knowledge left her feeling devalued and powerless,

'they didn't tell me. You know they were doing it silently [HIV test]....'

The diagnosis came as a terrible shock for Ria. She struggled to deal with the news that she has tested positive for a virus that she associated with death. Her immediate thought was for her children and their wellbeing in the event of her death. She also worried about how she would cope with ill health and the possibility of stigma. HIV disrupted her life, as she struggled to come to terms with it. She felt a sense of

betrayal at her husband for infecting her and she thinks he had been aware of his own HIV status and had deliberately infected her,

'my husband was avoiding me... he was so aggressive that I have forced him to the wall and I know where I got infected.'

Ria's life can be viewed as a book with chapters and in one of these chapters, her diagnosis was the first step in a gradual process where she incorporated an HIV identity into her biography. The other chapters in her book includes marriage, giving birth to a baby and separation from her husband. Another chapter was added to her book detailing a brief reunion with her husband and the arrival of another baby who is HIV negative. Widowhood constitutes a key chapter of Ria's life and her struggles to cope with being an abandoned wife, a single mother and an HIV positive woman. Ria reflected on her marriage during the interview,

'He had not been communicating, he just abandoned me with the baby, he left. I moved on with my life. Later.... He came back, it was a battle between me and him... I say I would no longer be his wife again, that he left me and the baby, I say since I got married, I.....the church counselled us and I welcomed him. When I welcomed him, I told him that we should go to test. By then, I was ignorant of HIV. He refused. He now went back and reported me to my reverend that I refused him as a wife and he now called us in again. We sat down and I accepted him. I accepted him and I took in with my last one.'

Ria emphasized how her diagnosis changed her view of herself and how she thought her life was coming to an end, as Ria remembered that at the time she was diagnosed, HIV was referred to as 'quarter to go', a reference to the fact that it was only a matter of time before death came. When she asked her husband to take a test, it was for other sexually transmitted diseases and HIV had not cross her mind, *'By then, I was ignorant of HIV.'* Her reference to a test suggests that she was aware of the possibility that her husband might have had other sexual partners during the years he was absent from her life and she was keen to protect herself from sexually transmitted diseases.

Ria's husband and church did not share her concerns and in fact, her husband was even offended at the suggestion of taking a test because it implied a lack of trust. Both Ria's husband and pastor were more interested in her continuing with a

marriage that she was no longer keen on and her church pastor in fact emphasized the importance of marriage, forgiveness and acceptance. Divorce is not something that Nigerian society and religious institutions are keen on. Women are urged to be submissive to their husbands and in Ria's situation, her pastor pleaded with her to forgive her husband for abandoning her and her child for so many years. The pastor urged Ria to reconsider her plans for divorce.

Ironically, at the time Ria tested positive, churches in Nigeria preached fidelity and safe sex as important tools against HIV and other sexually transmitted diseases. Churches made HIV tests mandatory for couples as part of pre-marriage counselling before they would permit the marriage to take place but that message was absent from their advice to Ria in urging reconciliation with her husband. The dominant patriarchal culture that characterizes Nigeria has exacerbated women's inability to negotiate safe sex. Firstly, women are expected not to refuse sex to their husbands even if they have suspicions that they may be at risk of being infected, as Ria's account here demonstrates- Ria's husband had even reported Ria to their pastor for refusing sex on several occasions. Secondly, there may be violent consequences if a woman was to suggest condom use or refuse sex with her partner (Ramjee & Daniels 2013). In Northern Nigeria, there is a strong cultural tradition of early marriage, low levels of female education and for Muslim women, female seclusion. A strong social pressure is also exerted on women including widows to remarry- as Rhine (2016)'s anthropological thesis noted, it is not unusual for women to marry numerous times following divorce or the deaths of their spouses. The fact that Ria reflects on her marriage suggests that it was a very important event in her life and it was an important way of explaining and making sense of her present situation.

Ria admitted that it took her sometime to reconcile herself to HIV because she thought she was going to die and did not see life with HIV worth living, particularly as a woman who has no status in society,

'in those days, I was thinking that I will die o. I was thinking that I have nothing, that I was not important in society, that was what I thought of myself'

She explains that at the time, the public discourse on HIV associated it with promiscuity. She questioned why she was infected with HIV and was very angry with her husband for infecting her,

'Why, I was thinking that why should this problem come to me? One, I'm not flirting, two since my husband left me, I have not been meeting men but this man came back and met me and I took in with my baby, they now tested me as HIV+, why should it be so? Why should it be so?'

Ria was at first in denial about HIV. Coming to terms with illness is a gradual process that starts with denial and resistance before moving on to the new reality of an illness. With time, Ria began to understand that with medication, HIV is a manageable condition. With time too, Ria forgave her husband for bringing the infection into their home. Through forgiveness, Ria was able to overcome her sense of powerlessness and regain control over her life course living with HIV. Forgiveness allowed Ria to move on and to make sense of HIV. She was prepared to continue the marriage, but only on her own terms,

'right from day one, when my husband called me when I took in, I say I have forgiven him, that was my choice.'

In the end, her husband refused, abandoned her for the second and final time and he died alone in hospital, far away from Ria and their children. Ria was unable to claim the widow's benefits that she was entitled to as her husband's complicated life meant that other women claimed to have been married to him and she did not have either the strength nor money to take legal actions to claim what was legally hers; in the end, this left her living life in poverty with her children.

5.2.2 'I felt bad from the beginning because I wasn't expecting it'- Halimatu

Halimatu was diagnosed HIV positive in 2003 after several months of illness, which came on and off,

'nine months because it started and I go to the hospital and they would treat me with some drugs and I would come back home. I would go back to the hospital so the third time, my dad say, 'ah, this treatment has not been working and we have been going to the hospital and your husband is late, let's go and find out what happened.'

Halimatu was at first diagnosed with and treated for tuberculosis but she was not getting any better and could not understand why, despite taking prescribed drugs she took as instructed,

'I was having pneumonia, cough, fever all the time, off and on, off and on.'

As TB is a common opportunistic infection that can accelerate the progression of HIV infection, it seems likely that the doctors suspected that Halimatu had HIV and had tested her for HIV without her knowledge. Halimatu's father observed that her treatment had not been working and suspected that since her husband was deceased, Halimatu's treatment warranted further investigation. This reflected not only her father's concerns for Halimatu but also that he may have had some suspicions about the nature of her illness since her husband also suffered from the same symptoms. It seems that the hospital revealed her HIV status to her father after testing her for HIV with neither her knowledge nor consent, similar to what Ria's recollection that in the early 2000s, hospital sometimes carried out HIV tests without patient consent. Halimatu stated that,

'they were treating me with TB and they didn't exactly tell me what is wrong with me. They only tell me that I had TB and pneumonia and it went on for a while...later on, my dad came and say, 'she has to know what is happening because if she knows, maybe she will even know how to prepare herself very well.' Then my dad, he didn't tell me directly, he bought me here... I now have a chat with a doctor....the doctor asked me to come in, I now come in, he say I should sit down, I now sit down. He now started questioning me...am I married? I said yes. How many children, I say one issue. And she now tell me, is my husband having two wives, I say no, only me. How long are we with my husband, I say just one year, because I married him. She now tell me did I see any symptoms like he is sick or anything, I say yes, I see symptoms; he has rashes, he is coughing like he has fever but he only tell me that it is cancer, so I thought that was what is disturbing him. She now tell me that did I know what the symptoms were all about?... she now tell me that if they find me with this sickness, how will I feel? I say, which sickness? She now kept

quiet for a long time. She now say if they find me with HIV, what would I do? I just collapse. I say, HIV? Where would I get HIV? I was innocent, I would go to school, my father is very strict, we don't go out, we don't do all sort of things, where would I get HIV? She now start explaining... anything that communicates with blood, blood transfusion, you can get HIV.... I don't do all these things.... You mean I'm going to die having my baby? No, no, you will not die but you will take in with drugs.'

The HIV diagnosis was distressing for Halimatu- she had just given birth and she was particularly distressed by the possibility that her baby could be infected too. Her reaction to discovering that she is positive conveys a sense of betrayal that her husband had deliberately hidden his status from her and the unexpected nature of her positive diagnosis. The gendered aspect of HIV is revealed in Halimatu's account, as she remember how her husband's illness disrupted her life, as she spent much time looking after him and then herself when she also began to fall ill herself,

'I feel very bad from the beginning because I wasn't expecting it. I had not even think of it, not even knowing this is what happened to him until they diagnosed me and they now called me and tell me this is why there is positive and he had even started medication.'

Halimatu's diagnosis with HIV shattered her previously held assumptions about herself, her identity and her future, particularly given her assumption that HIV only happens to those who do *'all sort of things.'* She stated that receiving an HIV diagnosis left her feeling bad as it was unexpected and with her own diagnosis, she finally understood what happened to her husband. Her statement, *'not even knowing this is what happened to him until they diagnosed me'* hints at betrayal and similar to Ria, Halimatu felt that her husband had not only hidden his illness but had deliberately infected her, which became more apparent when she found out that, *'he had even started medication.'*

Halimatu paints herself as an *'innocent'* victim who grew up in a home where her father *'is very strict.'* In Nigeria, HIV is not just an individual experience but also one that could impact on the family- Halimatu thought that people would view her family negatively because they failed to bring up their daughter according to socially acceptable standard of sexual behaviour. Halimatu, like Ria, was particularly keen to stress that she contracted HIV through marriage. Halimatu remembers that some of

the questions the counsellor asked during her HIV test, particularly those relating to her sexual life, puzzled her and she immediately associated HIV with sex,

'Where would I get HIV? I was innocent...'

Halimatu associated HIV with sexual immorality but she asserted that she had never engaged in risky behaviour such as having multiple sexual partners and taking drugs or blood transfusion which she described as '*all these things*' and she states at the beginning of the first interview that,

'it was after the delivery of the baby before I now know I am positive. I'm married to my husband.'

Halimatu made a distinction between contracting HIV through marriage and contracting it through '*all these things*' because she fears being labelled as a prostitute or sexually promiscuous. Halimatu also assumed that as her husband was a man with a high social status, which also accorded her some status as his wife, she was not at risk of contracting HIV.

The onset of chronic illness disrupted Halimatu's life through the months she had to give up school to focus on getting her health back and she had to move back home to live with her father and a stepmother with whom she had a rather cordial relationship; her HIV diagnosis was unexpected and came as a blow. She feared becoming a financial burden to her father as she was acutely aware that antiretroviral drugs were very expensive at the time even if her father could afford them. She began treatment in 2004,

'By then, the drugs were coming but if you pay it, it was N14,000 per month.¹⁵ And she [counsellor] say your daddy say he can afford drugs of N14,000. And I say, if he can afford drugs of N14,000, what about my junior ones that are in school? And he has a family and he has children..... He better go and take care of them and leave me, because I know I will die'

More than her own health, Halimatu was very concerned with lumbering her father with the financial costs of her drugs, as this could leave him unable to meet his

¹⁵ In 2004, N14,000 was the equivalent of £105.26 (Pound sterling to naira exchange rate as of 2004: £1=N133 (The unending woes of Naira exchange rate, Omoh Gabriel, 2014)

responsibility to her younger siblings. Halimatu cites her father as an important and valuable source of support. Similar to Ria's trajectory with HIV, Halimatu had a complicated pregnancy and doctors took advantage of her ill health to test her for HIV without her knowledge nor consent.

The gendered experience of power is notable in Halimatu's experience of discovering that she is HIV positive. Unlike Ria, however, Halimatu had an assertive male figure who insisted that she had to be informed about her HIV status even though he had been complicit in testing her without her consent and knowledge. In standing up for Halimatu to know the truth about her health, her father gave her some power and control over her life course and made it clear that the responsibility for her health laid in her own hands,

'she has to know what is happening because if she knows, maybe she will even know how to prepare herself very well.'

Halimatu's experience of testing for HIV contrasts with Ria's experience; the latter received her HIV status alone and then had to deal with the diagnosis without the presence of a supportive relative, unlike Halimatu. Both women shared similar gendered experiences of HIV- Ria as a mother looking after her children and herself alone after her husband passed away and Halimatu as a wife who took care of her husband before his death and then herself and her baby after her husband passed away.

5.2.3 'deep within my spirit, I am coming to God that I don't have it'- Irene

Irene was diagnosed HIV positive in 2003 when she went for a test as part of a mandatory pre-marriage counselling in her church,

'If I remember, it all started in 2003, but deep within me, I never accepted it.'

Irene refused to discuss the circumstances that led to her infection but her reaction to the test result was one of denial. Irene's denial of her HIV status set the pattern for

her life for the next decade, as she lived in denial. She was distraught when she fell severely ill with tuberculosis and pneumonia in 2012 and prior to treatment, had to take another HIV test which again turned out to be positive. For almost 10 years, Irene was able to keep her HIV diagnosis largely but not entirely out of her own awareness and two key themes shaped this initial experience with HIV. The first relates to her marriage- in the face of her HIV diagnosis, she went on to marry her then fiancé, thus facilitating her denial of her HIV status. Marriage gave Irene social status, which signified acceptance at the time by her husband. The second relates to lack of symptoms which further strengthened her initial denial of her HIV status until she fell ill in 2012,

'It was last May, I had an attack, attack in the sense that I had TB because I was coughing.... I keep on coughing, going to the hospital and they were thinking it was pneumonia. I met a doctor....he now say I should go and do test for HIV. That was when I had to confirm it again. After that, the doctor immediately say that I should start taking medications for TB.... It was last year that I started my anti-virals. For one thing, just in quote, not really in quote, let me just put it in open, I still don't believe that I am positive. Within my spirit, I don't believe it.

In her narrative account of HIV, Irene refers to the importance of her faith in God. She understands that she is HIV positive but her faith in God has to helped her negotiate her HIV status. She cannot control her status and she feels helpless and burdened by HIV but by putting her faith in God, she does not have to worry about it and in this way, overcome it,

Not that it is not positive- the result is there- deep within my spirit, I am coming to God that I don't have it. There are sicknesses that are more than HIV I am a Christian. My Bible tells me that there is no sickness that my God cannot cure..... me being positive, how will I start living my life, how will other people see me? But because of the courage that I have in my faith and in my God that I feel that I'm not HIV positive..... actually, when they diagnosed me again....it was a nurse that did it [HIV test] in the lab. She bought me the result, she asked me that if I should be positive, how would I take it? I will take it in good faith, I will take it in good faith because God knows why...deep within me...'

Irene started receiving treatment for tuberculosis in 2012 and she was forced to confront the HIV she had denied for years- before starting treatment, she had to take

another HIV test which confirms that she is indeed HIV positive- the result was a profound blow to Irene even though she was already aware of her HIV status,

'I have been trusting God for it, then why don't I take it in good faith? Is it not God that has been sustaining me all these years till this morning? So when she told me, actually I felt a bit bad but then I had to like, console myself.... I was just imagining myself thinking, 'this thing again, if people should know about it, how am I going to live my life again?'

TB was one of the opportunistic illnesses that Irene experienced in 2012 and further tests confirmed that her CD4 counts were very low and she had to start taking her ant-retroviral drugs then. Beginning treatment however signalled the end of Irene's marriage. Marriage had given Irene status and identity but divorce removed the social protection and respectability that she had achieved because of her marriage. Divorce also signalled rejection from her husband. The onset of illness, reaffirmation of her HIV status and divorce strengthened her faith in God, as she reflected on how, *'I have been trusting God for it, then why don't I take it in good faith?'*

In defining her response to HIV, Irene rejected biomedical knowledge in favour of another explanatory system, namely a spiritual one. She does not dispute her HIV status since she had already take at least three HIV tests prior to our interviews but she does not want a medical diagnosis to influence her perceptions of HIV; instead, she draws upon her Christian beliefs to explain her illness, stating that,

'I will take it in good faith, I will take it in good faith because God knows why.'

For Irene, a spiritual explanation offers a more logical explanation as it sits somewhat more neatly with her Christian worldview where HIV/AIDS is seen as a spiritual attack that can test one's faith in God, as can be gleaned from her statement,

'I am a Christian. My Bible tells me that there is no sickness that my God cannot cure.'

Irene's reference to the fact that *'there are sicknesses that are more than HIV'* also emphasizes her rejection of the stigmatising aspects of HIV whilst reflecting a desire for continuity in her life biography. Irene fears being stigmatised if she discloses her

HIV status because stigma is a devaluing attribute. HIV has also affected her relationship with her family, as she feels that has let her them down, particularly her parents and this deeply troubled her and left her with feelings of guilt,

'I know my dad and mom- my dad was disappointed actually. My dad was disappointed in me; my mom was so sorry for me though initially like my dad, she was angry with me...'

Irene's parents were angry with her not because of her HIV status but because she had kept her status secret for so long. Irene's fears surrounding the potentially negative fears of HIV disclosure on her relationships impeded her own acceptance of her HIV diagnosis over a long period, with significant costs to her sense of self and her health. At first, Irene kept her HIV diagnosis largely but not entirely, out of her own awareness when she first tested positive, as well as she could, in part by denying that she is positive, although this was a struggle,

'I think that in 2004,5, I did a test, then after that, I didn't go again for another test again. I was just living my normal life among all other things, just trying to avoid things that I know will put me down.'

Irene had a long and difficulty trajectory in accepting her diagnosis and her case highlights how accepting one's HIV status can be a long and complex process for many people, sometimes with serious consequences for one's health. Irene lived in denial of her HIV status because she feared the social (and even economic) consequences of disclosure yet her HIV status was constantly on her mind, as noted from her account of taking another HIV test in 2004/5. This denial nearly proved fatal for Irene, as it meant she was also putting off treatment and by the time she started her medication, her CD4 count was so low that had she not started her treatment at the time, she would have died.

5.2.4 'I didn't find it easy. I'm thinking that that is the end of the world'- Grace

Grace experienced recurring migraine headaches for many months and went to hospital where medical staff advised to take an HIV test. She received her HIV diagnosis in 2006 and so devastated that she immediately thought of death,

they did the test to me and they found out that I'm positive.... I didn't find it easy. I'm thinking that that is the end of the world. I'm thinking maybe tomorrow, I may die. That very moment, I'm thinking that's the end of my life.'

The HIV diagnosis was so devastating and unexpected for Grace that her first immediate thought was death. AIDS had already fundamentally altered Grace's life prior to her diagnosis with HIV- her parents passed away from AIDS-related illnesses and she therefore framed HIV in terms of the suffering and pain she witnessed from her mother's experience,

'Even my mother, I'm the one that took care of her.... I was in JSS [junior secondary school] at the time, so I now came back and I was taking care of her. She really suffered.'

Her mother's diagnosis forced Grace into a world of emotional and psychological pain. Grace had to drop out of school when she became her mother's primary carer and the whole family had to endure humiliating gossip by others in the community about her parents' illness,

'But that time, we were just hearing it in the village that she has positive but she didn't open her mouth and tell us that this is what is disturbing her.'

In Grace's account of watching her mother die of AIDS, she stressed how her mother 'really suffered', something that she feared she would experience herself in associating HIV/AIDS with 'suffering' and with death. She also associated HIV with stigma and gossip,

'We are hearing our people, our people outside there, they are telling us that our mother is HIV, that is why she is suffering like this.....she really suffered. She even died in my hand. She died in my hand but she really suffered before she died.....'

Grace mentioned that she had experienced frequent headaches prior to her HIV diagnosis- this pain was not just physical but also a sign of psychological distress, for which she has never received help. Her awareness of the social construction of HIV/AIDS meant that when she was herself diagnosed HIV positive, she had subconsciously internalised the negative perception of HIV as a death sentence and

a stigmatising condition and she also feared coming under the same social scrutiny that shaped her parents' experience of HIV.

Grace's sense of shame and anger was further compounded by the way her father's relatives dispossessed her, her mother and her siblings of her father's belongings after his death, her own difficult pregnancy and the subsequent breakup of her relationship with the father of her child. In taking away her father's belongings and in denying her mother the inheritance that she was due as his widow, Grace, her mother and her siblings were left destitute. Poverty compounded their financial hardships and left her mother struggling to feed Grace and her siblings. After her mother's death, Grace and her siblings had to live with some of these same relatives who reminded Grace of her loss. Each of these tragic events (her parents' diagnosis, dropping out of school, her caretaking duties, the death of her parents and her own marriage and divorce) altered her biography and sense of self which resulted in a suicide attempt a few years later.

Reflexive thoughts

In describing the circumstances that led to being diagnosed with HIV, Grace became emotional and cried during the interview. I stopped the interview to give her a break and to allow her to decide whether to continue with the interview but she insisted on continuing. She admitted afterwards that it was the first time anyone had ever given her an opportunity to talk about herself and her emotions about the diagnosis with HIV. Talking about the circumstances including her parents was an emotional one for her and she wanted to talk, to unburden herself. It was clear that Grace needed additional psychological support but she was reluctant to obtain from it her clinic. With her support, I approached a clinical psychologist who agreed to offer free sessions and for as long as Grace both needed and wanted it; the psychologist made it clear to Grace that these sessions would be confidential. I was moved by Grace's stories of the pain, suffering and humiliation that her family suffered but I took care not to show my emotions so that Grace would not be distressed.

5.2.5 'I cry, I no dey eat food, even sleep, I no sleep'- Talatu

Talatu tested positive in 2007 and articulated her experience in Nigerian pidgin English. She described the chronic illnesses that prompted her to take an HIV test,

'The time wen I know...I will feeling headache, stomach pain, diarrhoea...small rashes...'

[the time I found out, I was having headache, stomach pain, diarrhoea... some rashes]

Receiving an HIV came as a profound shock to Talatu and her immediate thought was death because she understood HIV to be synonymous with death,

'I cry, I no dey fit eat food, even sleep, I no sleep. Even myself ma, I dey fear myself. I think say the person wen dey get this sickness, life don finish...I dey fear myself.... I cry here, cry here, cry here.'

[I cried, I couldn't eat, even to sleep, I couldn't sleep. I was even afraid of myself. I thought that a person with HIV would die... I was afraid of myself.... I cried and cried and cried]

She is also aware that the social discourse of HIV as a sexually transmitted disease that could leave her open to stigma, ridicule, discrimination and rejection by others,

'I think say I wan die, no any future life again. I just dey fear myself...I dey hear the thing wen dey pain me for my life....you know say some people talk say if you get HIV, na only die, make it just remain the time wen you go die, I think say he be so.... You know say some people, if they hear say you get this sickness, everybody go run around you, even you give them food, they will say no, you give them anything, they will say no.'

[I thought I was going to die, that I had no future, I was afraid of myself... it really pained me... you know that some people say that if you have HIV, it is just left for death, for you to die, I thought that was it... you know if some people find out that you have this sickness, they will run away from you, even if you give them food, they will reject it, if you give them anything, they will reject it]

Talatu feared that the HIV diagnosis could threaten her role as a mother and a wife, roles which she considers crucial to her sense of identity- her fears also reflect her dependence on her husband because her parents died when she was young and she had no other support system in place. In the event of divorce, she faces the possibility of life in poverty and probably without her children,

'I just go and ask my husband, 'do you know HIV'? He just tell me yes, it is just fever. I say fever?.... me, I just keep quiet, I no tell him anything.... I just think say if I tell him, he go say no marriage again, I am woman, I

have...mmmm... my parents, all they are died. I have no anywhere, people where I will go unless him my husband. This is why I just fear.'

[I went to my husband and asked him, 'do you know HIV'? he just told me, yes, it is just fever. I say fever? I kept quiet, I couldn't tell him anything.... I thought that if I told him, he will divorce me, I am a woman, ... my parents are dead. I don't have anywhere or anybody else except my husband, that was why I was scared]

Talatu's response to HIV is borne out of her own reality of her situation and her understanding of what happens to women who are divorced. Her sentence, *I am woman* points to the gendered experience of HIV for some Nigerian women. In contrast to Irene and Halimatu, Talatu understands herself to be a woman who has nowhere else to go to in the event of a divorce. Irene for example returned to live with her parents after divorce but Talatu does not have the same option as her parents are deceased. In Nigeria, divorce is not kind to women, irrespective of the circumstances. Divorced women in Nigeria stand to lose not only their marriage and their homes but also their children, as divorce tends to favour men. Talatu's social identity is linked to her marriage and to her children. She is unemployed, illiterate and has no means of livelihood beyond her family sphere. A divorce could potentially make life precarious for her in a country where the majority of people live below the poverty line and poor women are particularly vulnerable to socio-economic and cultural exploitation. In addition, divorce carries huge social stigma for women, particularly in Muslim Northern Nigeria.

For Talatu, divorce could cause additional social complications, as she is a convert to Islam and it is likely that her husband would retain custody of their children. Northern Nigeria has experienced years of religious tensions between Christians and Muslims and some of these tensions have spiralled into violent clashes between the two religious communities which Talatu herself witnessed as a child growing up in the old Gongola State before the Nigerian government split it into three to create new states in a bid to reduce ethno-religious tensions. Therefore, Talatu has to walk a tightrope between two religious groups with neither particularly willing to accept her, as I observed from the criticism she received from other women who gossiped about her at her treatment centre. She was criticised for converting from one religion to another although several of her critics were themselves from mixed religious

backgrounds. Talatu was reliant on her husband to provide financially for her and her children and when she received her diagnosis, she was afraid that he could divorce her and deprive her of contact with her children. Talatu understood that it was easy for men in her adopted community to divorce women simply by uttering the words, 'I divorce you' three times.

Talatu described her initial lack of courage in telling her husband that she received an HIV diagnosis. To overcome this, Talatu called her biological sister to inform her that she had tested positive for HIV and her sister in turn called Talatu's husband to tell him. His response was one of acceptance and empathy but it also reflects the power dynamics at play in Talatu's marriage. Her husband took the major decisions that affects Talatu's life. Her husband negotiated access to treatment for her and facilitated her ability to access treatment by providing her with transport fare to the clinic to collect her drugs. He also provides the funds for her to purchase the foods she needs to sustain her ART treatment.

'I just call my sister tell her so she come say make I just keep quiet for my mouth sharp'- [I called my sister to tell but she told me to keep quiet]

'She say make I keep quite make I no tell anybody unless my husband...she call my husband, she ask my husband, 'you tell your family'? my husband say no. My sister say make he no tell anybody unless you and your wife. Then my husband say no problem because I like my wife, I will not tell anybody unless my wife, she loves me, she loves our children that why I just tell. I just say thank you.' [she told me not keep quiet, not to tell anybody expect my husband....she called my husband and asked him, 'have you told your family members?' and my husband said no. My sister told him not to tell anybody else- it is between you and your wife. Then my husband say no problem because I love my wife, I will not tell anybody, she loves me, she love our children. I just say thank you]

In describing the circumstances that led to her infection, Talatu explained that a sick relative requested her help and her husband gave her permission to spend time caring for this relative. The relative later died of AIDS and Talatu had not been aware of the relative's illness until this relative passed away. It seems that other people in the community gossiped about the nature of this relative's illness, as Talatu stated her friend advised her to take a test and check to know her status. To her shock, she

tested positive. She stated that her diagnosis was so shattering that she was unable to eat nor sleep that day and experienced self-fear,

'I cry, I no dey fit eat food, even sleep, I no sleep.

When Talatu finally summoned the courage to approach her husband, he responded by framing it in spiritual frames,

'he say just make I hold it and hold my God with myself because anytime, any day, any hour, I will still die, because of this sickness no. if my life is finished, I will die, no be because of this sickness'

[he just advised me to hold on to my God because anytime, any day, any hour, I will still die but not because of this sickness. I will die, not because of this illness but when my time is up]

For Talatu, her husband's acceptance was important because it made easier for her to accept her HIV diagnosis. Talatu's husband advised her to continue to have faith in Allah because only Allah can decide her destiny including the time and cause of her death and with or without HIV, one must still die. Talatu's husband comforted her by telling her that HIV will not lead to her death and even if one takes medication for an illness, one's life is still in the hands of Allah. Nevertheless, Talatu herself understands the need to take her medication as prescribed or else she could die of AIDS,

This sickness no dey kill people unless I no take medicine.

[This sickness does not kill unless I don't take my medication]

Talatu, together with her husband and Talatu's sister decided to keep Talatu's HIV status secret, to protect her and her family. If her husband's relatives were to know of Talatu's HIV status, they could pressure her husband to divorce her but it also appears that they wanted to protect the family from social scrutiny, stigma and discrimination from others in the society.

Aside from her own diagnosis, Talatu is also distressed that one of her children is HIV positive, having contracted it from her as she was pregnant when she cared for the relative who passed away from AIDS-related illness. Talatu mentioned in passing

that she feels guilty about her child's HIV status, as she is aware that her child contracted HIV from her during pregnancy and she takes elaborate measures to protect herself and her family by describing their drugs takes as 'sweets' and not informing her other children of their HIV status. She describes monthly visits to her treatment provider as parties where children collect sweets but she could only take one child.

Reflexive thoughts

Talatu's first interview had to be repeated as the tape recorder malfunctioned but I had taken notes during the first interview. Smith and Osborn (2007) recommend taping interviews as it is the only way to meaningfully capture what a participant says. This is why I had to repeat the interview again several weeks after the first interview and with the notes from the first interview, I was able to reconstruct Talatu's story. But rather than just interviewing all over again, I integrated both first and second interview schedule together to achieve a sense of continuity and to reduce potential stress on Talatu. Talatu found communicating even in pidgin English difficult and there were times I found it difficult to break down words in a way that she could understand. Was this down to the way I carried out the interview? Or did I use words that were too complicated? I was shaken by the revelation that Talatu is the mother of an HIV positive child- this was not something I had given much consideration to during the initial design of my research and was therefore unsure how to fit this information into my thesis. In the end, I decided not to question her about her child as I felt that this could cause her some distress and I was mindful that my research is about women, not women with children. Moreover, I had already informed Talatu's husband of some of the questions I would be asking as part of the research- their child's HIV status was not part of these questions although Talatu herself could have refused to answer questions relating to this, if she did not want to answer. I was aware that Talatu would discuss the questions I asked her with her husband and there is every possibility that he could ask Talatu to drop out of the study if he was not happy with the interviews, so I had to tread carefully.

5.2.6 'I felt the ground should open up and close me up. I felt like screaming'- Pamela

Pamela described the circumstances that prompted her to take an HIV test; she had developed a growth, which failed to heal despite months of taking medication,

'Ok, actually something behind my neck which I thought was a growth and I kept complaining....so I saw my aunt to the hospital on that fateful day and...on reaching the hospital, I was like, ok, let me take the opportunity to

run a test. So I ran a test. The process of running a test, it was a normal test, they say but I actually asked the laboratory, the guy who runs the lab, to run an HIV test..... I wasn't scared. I wasn't expecting anything but on reaching the doctor's office, when the doctor asked my aunt to excuse us, before she went, he spoke to me and I knew I was positive... I know that it was positive.'

Pamela had previously taken HIV tests and had tested negative on those occasions; she '*wasn't scared*' and therefore assumed that she would test negative on this occasion as well. She had not bothered to book for an HIV test with a counsellor. Instead, she asked the laboratory to run an HIV test in addition to some other tests the doctor had recommended as part of a health check.

Pamela is familiar with the process of testing and diagnosis for HIV and she realised that she had tested positive for HIV because, '*the doctor asked my aunt to excuse us.*' Her aunt had not been aware that she had taken an HIV test and the doctor did not want to share the result with Pamela's aunt without Pamela's consent. Pamela described her reaction to her HIV diagnosis,

'I felt the ground should open up and close me up. I felt like screaming. I felt like screaming out loud, like crying hell but the fact that I was with my aunt, I can't do that because I would not want her to know this is the situation, so I had to like hide it in me, it was more terrible. The pain was not funny. From there, we went to the market, that was when I was able to cry, cry to myself and when we got home, I had to like, excuse myself and told my mom I was going to church. Really, I wasn't going to the church, I was thinking of running away, where I don't know. I just picked my handbag and was going to run away. I was able to talk to a friend and he calmed me down but I have never thought of suicide as an option, that's one point I should be clear on.'

Themes including shock, fear and resistance are clear from Pamela's account of the day she tested positive. Pamela's HIV diagnosis came as a shocking blow, as implied in her statement, '*I felt the ground should open up and close me up.*' Pamela experienced an almost overpowering sense of shock and fear when she received her HIV diagnosis but because her aunt at the hospital with her and had not been aware that she had taken an HIV test, she had to compose herself and followed her aunt to the market as planned.

Pamela maintained her composure in her aunt's presence and in the marketplace but inwardly, she was very distressed by her diagnosis. Her first impulse on getting home was to leave the house- she had difficulty telling her mother that she had tested positive for HIV. She described the day she received her HIV diagnosis as '*that fateful day*', a clear indication that it was a day that had a terrible effect on her- that day, receiving an HIV diagnosis was a life-shattering event. The diagnosis was so shattering that she considered running away from home. The fact that Pamela mentions her mother suggests that her mother is an important figure in her life yet she felt she could not face her mother because she was not sure how her mother would react. Pamela's mention of her mother suggests that the mother-daughter relationship is a powerful one and it is also a gendered experience- the mother-daughter relationship is an important primary relationship which has significant implications for caregiving, as caring for other family members is a task that often falls on women. Pamela sees her mother as an important figure whose presence and support she values but at the time she was diagnosed with HIV, she could not face her mother. Instead, it was easier to talk to a friend who gave her some time and space to cry and to talk about her HIV diagnosis.

5.3 Summary of theme one: testing positive

In this chapter, my research draws out accounts of the women's experiences of testing positive. For some of the participants cited there, prolonged illness prompted them to take HIV tests leading to the diagnosis of HIV. They often reacted with shock, anger or denial. In all cases, an HIV positive diagnosis came as an unexpected blow, which affected their lives. For women who were already struggling to deal with other life issues such as marital separation and reconciliation (Ria), widowhood (Halimatu) and orphanhood (Grace), testing positive for HIV was a blow to their sense of identity and for Talatu, in addition to dealing with her own status, she has the added stress of caring for an HIV positive child. Today in the global North, HIV is a chronic illness and PLWH can expect to live a normal lifespan similar to that of people who are not HIV positive. In Nigeria however, the reality is that the majority of HIV positive people still do not have access to medication. HIV is

experienced not just as an individual event but also one that impacts the whole family.

As I observed from the field, there is still widespread misunderstanding and stigma surrounding HIV/AIDS in Nigeria, which affects the lives of PLWH. Particularly for women like Ria, Halimatu and Irene who tested positive in the early 2000s, the broader social perceptions of HIV had an impact on their sense of self as they were forced to confront issues of death and dying from an illness with no cure. Death is not just on a physical level but also psychological with the threat of stigma, discrimination or rejection from one's husband even if he is the source of their infection.

During the early years of the epidemic in Nigeria, HIV/AIDS was constructed in terms of negative metaphors that were used to interpret the meanings of HIV- HIV as a killer disease that has no cure, HIV as a punishment for sexual immorality, HIV as a war on society and HIV as a disease of otherness; one of the earliest accounts written on HIV in Nigeria noted that stigma against people who tested positive in the early years was pervasive (Alubo 2002). There was little understanding about the nature and dynamics of HIV and most people, particularly women underestimated their own risks. It was quite common for hospitals to test patients for HIV without their knowledge or consent and for patients like Ria and Halimatu who tested positive during the early 2000s, the lack of consent to test represents a form of powerlessness and devaluation of self as women who could make their own decisions about their health.

Things were no less easy for women who tested positive from 2005, the year contribution from the PEPFAR helped Nigeria to extend treatment cover for PLWH. HIV/AIDS was still associated with death but the women could have access to free ART medication to minimize the symptoms of HIV infection. The participants had experienced varying degrees of biographical disruption that are highlighted in their accounts. For some, the disruption was only temporary but for others, it remains ongoing. For most, being diagnosed positive shattered their previously held assumptions that HIV was something that only happened to the promiscuous, homosexuals and drug users. A positive diagnosis struck at the very heart of their

identity as mothers and wives in a society where marriage and motherhood are the very principles that defines what it is to be a woman.

Powerlessness was already a key theme in the lives of women even before their HIV diagnosis. Gender inequality and cultural beliefs regarding sexuality have increased Nigerian women's vulnerability to HIV by preventing them from taking steps to reduce their risks of contracting HIV, such as negotiating condom use. HIV sometimes amplified this powerlessness, particularly during the early stages of diagnosis where hospitals and treatment providers seem to exercise some power over the women who had no say in and over these encounters. The women's sense of powerlessness too was also amplified by society's response to their diagnosis, with many experiencing stigma and discrimination because of their HIV status. The women therefore internalised the negative social perceptions of HIV which has affected their self-perceptions as women living with HIV. HIV breached their sense of self and disrupts their taken for granted assumptions about their health, bodies and sense of self- it changed the women's relationships with themselves and their worlds.

Chapter Six: Theme two: Living with HIV

Overview

This overarching theme explored the impact and meaning that participants ascribed to HIV. The participants spoke of the challenges that they experience with HIV; subthemes such as normalisation, acceptance, relationships and sex are all explored as part of the disruption of the women's self-explanatory systems. This theme also highlights the women's struggles to make sense of themselves in the face of existing and shifting challenges because of their HIV status. Women are exposed to real and imagined stigma, are rejected for their HIV status and for unmarried women in particular, being HIV positive had an impact on marital prospects and future motherhood, which are forms of biographical disruption that shattered the previously held assumption of themselves and their identities. Both married and unmarried women felt that they were as promiscuous by the wider society even though they were infected by their spouses or may have contracted HIV from methods other than sex and or had only ever had one sexual partner whom they were faithful to.

6.1 'In fact, honestly, it wasn't easy for one to be positive'- Cher

Cher reflected on the impact that HIV had on her life during the first interview,

'Well, I can't actually say that HIV has an impact in my life because it hasn't reduced anything in my life. My life remains normal, I'm doing my normal activities and I can do what people who are not positive are doing, that means a lot to my life.'

At first, Cher denied that HIV has had an impact on her life, which she insists, remains 'normal' and that HIV hadn't 'reduced' anything in her life but as our encounters progressed, it began apparent that she was experiencing challenges in her life which began even before she was diagnosed with HIV,

'I can't tell lie, I didn't find it easy, I felt terribly bad, I felt terribly bad because I'm a mother that has been taking care of a disabled childbefore I discovered my status.'

Receiving an HIV diagnosis was devastating for Cher as she was also having to care for a profoundly disabled adult child. She was very troubled by her child's severe physical and mental disabilities and she admitted it left her feeling depressed- caring for her child was hard, stressful and lonely as she is his sole carer. In addition to this, she had already lost a child whom she suspected may have died of AIDS, as she remembered that this child was always sick and her doctors were unable to tell her what was wrong with her baby. Her child died at least five years before she was herself diagnosed with HIV and Cher remembers that she herself had also experienced long periods of chronic illnesses including diarrhoea and fever; she did not seek medical help, as she was preoccupied with looking after a disabled child and a sick baby. She had gendered experiences of life as a mother whose preoccupations with meeting the needs of those two children left her unable to meet the needs of her other children who did not have health challenges and this in turn left her feeling stressed and guilty.

She is ambivalent about her HIV status and frames HIV in negative terms even though she initially denied it had an impact on her life. She has internalized HIV as a sexually transmitted disease and has sought to defend herself against this negative image of HIV by emphasizing her own moral values. She insists that she has never been intimate with any other man apart from her husband,

'I try my possible best to see that I live godly life in my marriage without defying my marital bed. I have been trying my possible best with the help of God. But today, I'm HIV positive, that doesn't mean it's the end of my life. I still have my life to live, that's why I should live a holy life now and shun evil. If I was living a dirty life, that I'm HIV positive, it has to bring me back to my Creator to stop the bad things that causes HIV.'

Her views on HIV are somewhat contradictory, suggesting that she engages in a mental battle with HIV. On the one hand, Cher states that HIV is a result of a '*dirty life*' but on the other hand, she rejects the notion that she has ever been unfaithful to her husband. She stresses that she contracted HIV within the context of marriage and attributes her infection to her husband- it was his '*dirty life*' that led to her being infected with HIV. Cher is consumed with anger and bitterness towards her husband,

not just for infecting her but also for the emotional and economic abuse he inflicted on his family- Cher complains that her husband does not provide for them but she however refuses to contemplate divorce as she feels that marriage is something that has to be endured; she had married for 'better or for worse', and even though she is angry that her husband infected with HIV, she decided to remain in her marriage. The decision to leave or stay in her marriage is hers alone- only she has the power to make this decision regarding her marriage even though it is an extremely unhappy one where she experienced emotional abuse. Cher is also angry that some of their friends failed to tell her that her husband has been unfaithful even though in reality, it was probably not their place to do so.

Apart from HIV, Cher's biggest struggle is the need to meet ends. Cher previously worked as a volunteer for a non-governmental organisation for which she received a stipend,

'I am always fighting HIV and AIDS and under [organisation], I'm with that ministry, that's [organisation]

However, a shortfall in donations meant that the organisation had to cut back on staff salaries; it also meant letting some volunteers including Cher go. Cher was very upset by this- she had relied on the this stipend to make ends meet and it had been valuable in meeting some of her needs, including paying some of her children's school fees and providing food for her household. The stipend had given her some leverage over her husband, particularly as she explained that her husband did not always contribute financially to the household. Without this stipend, Cher fell on hard times.

Financial hardship meant that Cher could no longer afford to buy the food she needed to eat in order to build up her immune system and for her drugs to work properly- she often put her children's needs before hers,

'the thing that is bothering me is the need to make ends meet, how to help myself. I want to do something to earn a living; living from hand to mouth is not mine, I want to be out of it. Presently I'm managing to take care of a disabled child, it's not that easy.'

The need to make ends meet was not only financial but also had a psychological and emotional impact- it left her feeling frustrated, angry and helpless and there were occasions that she has suffered from depression. Cher feels that her husband is deliberately refusing to provide for their family even though he goes to work every day- she complained bitterly that he preferred to spend his money on drinking and womanizing.

Cher's financial struggles contributed to her defaulting on her first line treatment and she has been put on second line treatment with a warning from her clinic that it was the last line of treatment they could give her free of charge. Cher turned to her Christian faith to provide much needed comfort and explanation for the way her life was going. Living what she sees as 'a godly life' provided a form of relief but she rejects the notion that she led 'a terrible life' because she has always tried her best not 'to defy' her 'marital bed' with the help of God,

'In fact, honestly, it wasn't easy for one to be positive. The fact that I'm a married woman being positive, there is going to be real problems but I will give God the glory.....Since then, it has been really hard to live with it.'

Cher finds living with HIV extremely difficult- it affects her mind and how she saw her marriage and her husband. The broader social perceptions of HIV associates it with sexual immorality and this shattered Cher's self-concept, as she feels that she has always been faithful to her husband and she thought that married women who were faithful to their husbands didn't contract HIV; her faith in God offered her a way of defending herself against accusations of sexual immorality. HIV is hard to live with but Cher's HIV status strengthened her faith in God and it offered her a way of making sense of and explaining her status and her life in a broader and more spiritual sense. Her HIV diagnosis also left her feeling angry with her husband,

'Despite the fact that I knew I didn't play with my marital bed, I tried to keep my marital bed clean, in so far as I found myself to be positive. Why must I argue? I know of myself but I don't know of my husband's life.'

Her statements that 'why must I argue' indicates that she cannot question HIV in her life, but because 'I know of myself', she feels powerless- being infected with HIV is

out of her control- she has been a faithful wife but her husband has not been a faithful spouse and as a result, he has infected her. She now feels that because of her children, she has no choice about the future of her marriage and the stability of her family unit,

'I need to stay with my children and allow my marriage to continue, to forgive and to forget and let go. That was what I did.'

Cher's decision to remain with her husband reflects a gendered experience- Cher feels that a divorce would destabilize her family but it is also clear that even though her husband has not been contributing towards meet the financial needs of the family, a divorce would cause more hardship for her. Despite Cher's complaint about her husband's lack of financial support, he had built a large house for the family and had made provision for water and power and she could supplement her diet by growing fruits and vegetables in the garden. In Nigeria, divorce can make life precarious for women- Cher would have to leave her home and return to her parents who were themselves struggling financially. In such a scenario, how would she survive without support, which Cher was aware her husband would likely not provide? How would she explain to people about her divorce?

Cher feels that it is pointless asking questions about her life trajectory. She does not have control over her life course, so it is easier to accept her life the way it is and leave the rest to God because focusing on her problems would not solve anything. In coming to terms with HIV, Cher has accepted her diagnosis by rationalizing that she would not gain anything by being angry at her husband for infecting her; instead, it was easier to let go and not question her life,

'But if I say I will ask how come about this and how come about that, I know that nothing good will follow after that question, I just had to let go and leave the rest. He is the One that knows.'

Reflexive thoughts

During my encounters with Cher, it was clear that HIV had left a deep impact on her life and on her relationships. For example, she wanted us to meet at her house for our interviews, but when I visited her during a pre-interview encounter, I saw that there were several family members staying with her, which meant there would be no

privacy. I suggested to her that her home might not be the best place for our interviews and she became very upset. She wanted to know whether the fact that she is HIV positive and her state of her house (admittedly dilapidated) were the reasons for my suggestions. I explained to her that it would be better to use a neutral location such as the clinic for our interviews, as I wanted her to be feel free and relaxed during our interviews and her home was not conducive for carrying out interviews because her husband and other family members were around. Being at Cher's house made me realise that women are at the intersections of HIV, gender discrimination and poverty. Through my encounters with Cher, I became aware of the need to treat the participants with respect and dignity and to be sensitive to their needs and feelings. The experience of poverty, HIV and discrimination have marked the life of some participants and they were very troubled by this. I had to be careful in my dealings with the participants, to ensure that they are not hampered by our interactions. Cher and I shared interests in plants, herbs and education and she introduced me to other HIV positive women in the community. Cher spoke of how much her voluntary work meant to her as it gave her something to do outside her home and gave her some respite from her constant worries about her life. Cher was very sensitive about her HIV status and through my interactions with her, it became apparent that HIV dominated her relationship with her wider social world and left her sensitive to feelings of perceived rejection and stigma.

6.2 'I prepared my mind that what will be will be'- Rabi

Rabi tested positive in 2006. She spoke of her experience of testing for HIV, her reasons for doing so and her reaction to a positive HIV result and her life post-diagnosis,

'I was told I was positive in 2006... that was after he died and I now discovered that, so when he died, after receiving the death certificate....he died because he was HIV positive.... I now decided to go there [Jos University Teaching Hospital].... I am prepared ever since that day I saw it [death certificate], I prepared my mind that what will be will be, I have to prepare for my case... they counselled me and say HIV is not the end of the world.'

In her account, Rabi referred to her husband as a 'he' rather than 'my husband' which suggest her emotional and psychological distance from him; she also attempts to extend this distance to herself in describing herself- it seems that her HIV status made her attempt to distance herself from her past (which represents her deceased husband) and her present and future (herself as an HIV positive woman and widow)-

although the use of personal pronouns such as 'my' and 'I' in her language however suggests that she struggles to do this,

'Ok, emmm, this is hajiya from a polygamous family, eh then got married after finishing my secondary school, got married, had kids, divorce, then got married again, then into business, then now died the second one I got married to.'

Rabi identifies herself as a wife, mother and widow, multiples identities which have shaped her life both pre and post-diagnosis. She alludes to the lack of further opportunities in her life for education and to pursue a career. She got married after completing secondary school, had children, divorced her first husband, remarried and then became a widow after her second husband died. In alluding to herself, she also uses indirect language in describing how she grew up in a polygamous home with her father, his wives (including her mother) and several children- the use of indirect language here reflects suggests that growing up in a polygamous home was not a happy experience.

Rabi's brief description of life after her remarriage indicates that she had to work to support herself and children, which reflects the gendered experiences of being a woman in North-Central Nigeria. The ideal model in Nigeria is a man who works to take care of his family but in reality, many women have no choice than to take the sole financial and parental responsibility for looking after their children. In Northern Nigeria where polygamy is quite common, particularly among Muslims, it places women and children at a distinct financial disadvantage, if the man does not have the economic resources required to maintain his household- this leaves his family destitute, particularly if the women involved in polygamous marriages themselves have limited economic power.

Rabi's struggles with life continued after her second husband's death. He was hospitalized following a serious illness, which eventually led to his death. Rabi says that neither the hospital nor her husband discussed his illness with her, even though she had looked after him during his illness. His death certificate listed an illness that Rabi had never heard of and this prompted her to ask a nurse, who admitted that it was AIDS-related,

'The very first day I saw the, when I collected the death certificate, was the day I made up my mind so I know.... I wasn't feeling sick, I wasn't feeling sick.'

Rabi took her an HIV alone and since she tested positive, she has never disclosed her HIV status. Rabi has also never informed family members of the true situation regarding her husband. Rabi at first put a brave front to her HIV status by stressing that since she knew that her husband had died of an AIDS-related illness, she was prepared to face up to the possibility that she too might also be HIV positive. As our encounters progressed however, Rabi indirectly referred to feelings of anger and betrayal at her husband for deliberately keeping her HIV status a secret and thus infecting her,

'Even if the husband is alive, he might even, if he is alive or positive, he will not tell you that he is. Most of them, they will take medications without you at home knowing, that is happening in this our own society and community, so you know, the best thing you do is take care of yourself quietly to avoid other attacks.'

Rabi alludes to how common it is for HIV positive married men keep their status secret, infect their wives and start medication without their spouse's knowledge. Since testing positive herself, she has lived with the secrecy of her husband's HIV status- she had not been aware that he was HIV positive and had been taking medications, which he had hidden from her when he was alive. Whilst it is not unusual for widows in Rabi's community to marry for the third or even fourth time, her husband's actions shattered Rabi's trust in men and she decided that she would never remarry again nor pursue relationships with men,

'When I discovered the, when I discovered that I was positive, immediately ok, my husband died, you know this erm, 'male-female' relationship, I completely off, completely.'

Ironically, Rabi continued with her husband's secrecy in living with HIV. She has never disclosed her HIV status and has never told family members the cause of her husband's death because to do so would reveal her own status. Keeping her HIV status secret is a gendered experience- by keeping her own status secret, she is protecting her children and deceased husband. Rabi also cites stigma and the desire

to protect her children from gossip as a reason for this. Rabi is acutely conscious of the stigma and discrimination she feels she and her family could be face, if other people in the community were to find out that she is HIV positive. As a woman, she has had no control or power over HIV coming into her life through her husband but by keeping her HIV status secret, she could retain an element of control over her life, health and physical appearance; by looking after herself, she feels she could control the progress of HIV,

'Again it depends on how you take care of yourself that is what matters. Death, whether you are HIV positive or not, death will definitely, you are definitely going to die someday, so the issue of panicking, fear that because you are HIV positive, is like no, that shouldn't be my priority.'

Her statement also suggests that she has thought of death and has come to terms with the possibility of it. She states that death is inevitable, with or without HIV. Rabi fears that if she tells her children of her HIV status, it could have a psychological impact on them and she also wants to protect them from gossip,

'No, it will weigh them [her children] down, weigh them down, that's what I have just say now, as I explain to you, the way people marry, if I now say, you know, this is what I have, I know he or she will not say anything that my mother is sick but each time they fall into or go into and mix with people who are not, they will feel, I mean, it will have effects on them, you get it? So that is why I prefer to just, I mean God is in control and I believe in God, that He will do whatever so shall He do, so it will be.'

Rabi fears that the impact of disclosure on her family- it could affect her children psychologically and given that Nigerians tend to construct their identity collectively rather than individually, Rabi fears that disclosing her HIV status could have an impact on her children's relationship with the wider society. Rabi's word, *'the way people marry'* alludes to fear of stigma. She fears the effects of social stigma-disclosure could leave her family open to gossip, which would affect not only her but also her children and their marriage prospects.

In Nigeria, marriages are usually negotiated between families, even if the parties involved made their own choice of marriage partners. Once a couple decide to marry and the man informs his relatives who in turn approach the prospective bride's family

to negotiate on marriage on behalf of the groom. Both families investigate each other- does the bride have a good reputation? What is the health status of the family? Is there a history of health issues in either family? Is the family respectable? In this light of this, Rabi refused to disclose her status to her own children as it could put her and them under the social microscope. Rabi alludes to how stigma is based on ignorance- people within her society do not understand HIV and believe that HIV can be contracted by mere association with an HIV positive person,

'even if you are not infected, you are affected at least, somehow, somebody or maybe relatives or somebody else that is when they will now start, ah in my house o, this person, this person is HIV positive o....then secondly, the whole family, you are in trouble, most especially now that you are kids, if you have kids and have male children or even female children, their father is HIV positive o, don't go near them, if you marry from that family or if you make friends, you might go and contract it, some of them are ignorant, they think even from shaking hands, you get it, you get infected.'

Rabi also fears that HIV would have a negative impact on how others see her in the wider society if she discloses her status- this represents an important gendered aspect of HIV. In Nigeria, women have been considered as vectors who spread HIV. Rabi contracted HIV from her husband but as he had never disclosed his HIV status even to his own family members, this put Rabi in a difficult position after his death because she could be blamed for infecting him with HIV and it could lead to her being labelled, as HIV is strongly associated with sex in Nigeria,

'it is something that they understand or come to think that if you are HIV positive, most especially the women, automatically, you are a prostitute.'

Rabi feels that the way society views women with HIV and the association between sex and HIV places her on the defensive in having to insist that she is not and has never been unfaithful nor promiscuous. In navigating life with HIV, Rabi's non-disclosure makes sense for her because it enables her to maintain her relationship with her family and with her wider society. Through non-disclosure, she can also maintain her health and move on with her life. Non-disclosure gives Rabi some control in navigating her life with HIV but at the same time, secrecy meant that Rabi could not fully incorporate HIV into her identity. She could navigate life with HIV through non-disclosure and the medications, which she hides from her family but she

could not incorporate an HIV identity into her life course. The lack of an HIV identity also feeds into other aspects of her life and as a result, she refuses to attend support group meetings or even to make friends with other HIV positive women in the clinic where she receives her drugs.

6.3 'It is a raw experience'- Vickie

Vickie tested positive for HIV in 2005 after experiencing months of prolonged chronic illness that resulted in hospitalisation and she reacted to her HIV status with profound shock and disbelief,

'from the beginning, I didn't accept it to be sincere with you. I didn't accept it. In fact, I was thinking that they just exchanged my blood with another person's blood that has it, so how can I? me? Having it? I thought they exchanged my blood for another person's own...'

Her statement, *'to be sincere with you'* reveals the depth of the unexpectedness of a positive HIV diagnosis. Vickie thought that her life had come on an end,

'That day, I thought I would die.'

HIV is such a distressing and life-changing event for Vickie that she describes it as,

'a raw experience...yes.. I have never thought that I would have it and now I'm having it, so it is kind of let me say fears... I didn't expect to have it and now I'm in it, so I have to live with it... I accept it [now]'

Vickie at first thought that her life was over when she received her HIV diagnosis, as she felt that she had 'died' in explaining the psychological impact on her sense of self. The impact of HIV also fed into other aspects of Vickie's life. At the time of diagnosis, Vickie was in secondary school; before her diagnosis, she spent so many months dealing with illness that she could no longer catch up at school and dropped out of school to deal with her illness. Through chronic illness, Vickie lost an important part of her life as it caused a rupture by interrupting her education and prevented her from keeping in touch with her school friends. The HIV diagnosis further deepened this rupture by making her feel that she has no future, as she would soon die, so there was no point continuing with her education,

'Why I didn't further my education was I was thinking, wow, Vickie would die. I just say, I won't go. My mom keeps saying I should further my education and I just keep saying 'don't bother about me', I just learn how to dress hair. That's what I do.'

She has struggled over time to come to terms with HIV. Vickie wouldn't go into the circumstances that led to her infection but she blames herself for contracting HIV and feels disappointed with herself because she had heard about HIV yet had ignored warnings about it, particularly the aspect relating to condom use. Young Nigerian women are particularly vulnerable to HIV- they are more likely to be infected with HIV than males of the same age group and less likely to use condoms and are more likely to engage in risk-taking behaviour that leaves them vulnerable to HIV. Unprotected sex exposes young women to negative health and social outcomes including sexually transmitted diseases, teenage pregnancy, early marriage, abrupt termination of education and poverty. Vickie had heard of HIV before her own infection but she did not fully grasp the message on HIV, possibly due to lack of awareness about the need to use condoms and also a lack of understanding of HIV itself,

'I'm hearing about it, how HIV will kill. When I am positive, I say to myself. I was hearing about HIV, now look at me now, HIV is killing me'

Vickie contracted HIV at a time when the message and efforts around HIV/AIDS prevention in Nigeria was quite ambiguous and these did not address the issues of young people, sex education and sexuality. The lack of education and knowledge means that young women tend to lack power to negotiate safe sex and are more likely to take risks. HIV has fundamentally altered Vickie's views of herself and her plans for the future. During the first interview, Vickie insisted that her HIV status made her less interested in romantic relationships but during the second interview, Vickie's concerns about her future became more apparent- Vickie she wanted a relationship that would lead to marriage,

'I'm feeling pain, like how will I remain in pain? Being HIV positive and will I ever ma get married? That's the problem, that's just the situation.'

Vickie is keen to get married but being HIV positive has given her an unwanted label that could affect her marital prospects and motherhood. Although discussions with Vickie never directly touched upon the subject of sex, it was an uncommunicated part of the interviews. Cultural expectations of gender roles exerts enormous pressure on unmarried women to be morally sound- women are expected to abstain from premarital sex and to be virgins on marriage whilst men's sexual moralities are almost never questioned. The discourse on HIV/AIDS even in treatment centres, including the ones where women like Vickie, Cher and Grace are receiving treatment, has focused on premarital sex as a risk factor for HIV and these messages are often unintentionally directed at the women who are the main service users.

Vickie's HIV status is a constant worry to her because she feels that it has limited her marital prospects, signifying unfulfilled dreams and hopes. She had already been let down by an HIV positive man who had broken his promise to marry her and had instead gone on to marry another woman; her former fiancé's action left Vickie feeling emotionally wounded. Throughout the second interview, Vickie's main preoccupation was whether she would ever get married, something that reflects societal (as well as family and her own) expectations of her social role and identity in society. Her desired identity as a wife and mother would define her relationship to her family and society yet by not fulfilling these roles, she feels a sense of failure. It therefore left her *'feeling pain'*. Vickie's desire to marry points to a gendered aspect of HIV- she is a young HIV positive woman who wants to marry and to have to children but HIV acts as a barrier because with HIV, she feels that she is not a desired partner and she already had experienced a rejection in this regard.

There may be medication for HIV, which can help people live a normal life but Vickie is nonetheless frank about living with HIV by describing as

'It is a raw experience.'

The experience of HIV is raw because,

'I have never thought that I would have it and I'm having it now, so it is kind of...let me say fears... I didn't expect to have it and now I'm in it, so I have to live with it'

Although Vickie received her diagnosis in 2006, she was still very emotional in describing HIV as a *'raw experience'*, suggesting that the passage of time had not ease her emotional response to HIV which reveals an ongoing struggle in dealing with HIV. Staff at Vickie's treatment organisation expect her to move on in with living with HIV yet in reality, her memories of the events leading to the discovery of her HIV status are painful because it marked a rupture in her biography. Vickie's statement that HIV is *'a raw experience'* is a powerful description of HIV. For her, being HIV positive goes beyond the biomedical and her experiences must be framed within the broader social frameworks of how HIV is seen in Nigeria society, because her HIV status has huge implications for her future identity. HIV fundamentally altered Vickie's previously taken for granted assumptions about her life, family, body and future.

Vickie understood HIV to represent a rupture as she had to drop out of school, lost touch with her school friends as well as losing an important part of her life to dealing with HIV illness. HIV is a *'raw experience'* because it cause a rupture in her biography due to illness, experience of stigma and a loss of self. It also resulted in a loss of future expectations that she would marry and have children. Vickie's emotional response to HIV reveals ongoing struggles with HIV. Her memories of the events leading to her diagnosis are painful because it marked a rupture in her biography. For Vickie, memory is an important asset that enables her to connect her past to the present and hopes of a more positive future that her HIV status has threatened to scupper. Through her memories and recollections of the events that led to her HIV diagnosis, Vickie attempts to make sense of her past, present and future even though HIV is *'a raw experience.'*

6.4 'You have the fear of going into a serious relationship'- Pamela

Pamela was still struggling to come to terms with HIV and to define what HIV meant to her since her diagnosis in 2011. HIV affected her self-concept, particularly in relation to her attitudes to relationships with men. She was also struggling to regain her trust in men,

‘Seriously, you will feel like how you wish you were dead....in fact, you have the fear of going into a serious relationship with the fear that ok, if I go into a serious relationship, the person doesn’t even know about my status, once he knows, he will leave... because of this, it took me months before I could start one- almost a year if I’m not mistaken.’

Pamela’s statement, *‘seriously, you will feel like how you wish you were dead’* suggests that with HIV, she has experienced psychological death, which left her feeling ashamed and fearful about going into a relationship. She feels pressured to disclose her status to a potential partner yet she also fears that her partner could leave her because of her HIV status. Lack of trust in men and fear of disclosing her HIV status made Pamela more reluctant to pursue relationships with men.

Pamela also defined HIV in terms of sex, as she contracted HIV through sex. Prior to her diagnosis, she had found it difficult to negotiate condom use but being positive forced her to re-evaluate her attitude towards sex, relationships and her spiritual life. Cultural attitudes towards sex and sexuality makes it difficult for young women to negotiate safe sex. Firstly, Nigerians are generally not comfortable talking about sex, which makes it harder for young women to learn and to talk about sexual intimacy, relationships and sexual transmitted diseases. Secondly, gender and gendered roles often shapes power dynamics in intimate relationships between men and women. Women are expected to be passive and not to ask their partners to use condoms and their lack of knowledge and power to negotiate safe sex leaves young women at risk of contracting sexually transmitted diseases including HIV. Traditionally, women were socialised about sex and marriage through rites of passage ceremonies but colonial rule and the spread of Christianity led to a breakdown of these rites of passage for young people across Nigerian cultures, leaving women without power and knowledge when it comes to negotiating safe sex. Christianity introduced a new notion of sex by promoting sexual abstinence for young and unmarried people.

Pamela’s focus on sex points to a moral dilemma as HIV struck at the foundation of her religious faith as a Christian and left her feeling a sense of guilt that she had not insisted on abstinence (refraining from sexual relations) nor negotiated condom use,

‘well it has had a strong impact, especially in my spiritual life, emmm, my relationship life as well because now, it’s all about, if anything I struggle with

people, it always relationship with abstinence of sex which is not common with guys but with me being positive, it's easier for me to just push it out because I would, I promise myself one thing, I would never be a risk for somebody to be positive, yet the person that gave me was so heartless but me, I promise myself nobody will cry it's me, so that's just it.

With HIV, Pamela feels that she could push for condoms or abstinence. She understood HIV to be a sexually transmitted disease for which condoms are a necessity- with HIV, it was easier for her to negotiate safe sex so that she would not infect anyone else. Her concern to negotiate safe sex also hints at her anger at her former boyfriend, referring to him as, '*the person that gave me was so heartless.*' By blaming her ex for infecting her, she is shifting the blame to him; he is '*heartless*' and did not protect her from HIV by using condoms nor by disclosing his status. Pamela feels that she has to disclose her HIV status when starting a new relationship so that she would not infect her partner, '*I promise myself one thing, I would never be a risk for somebody to be positive*' yet her ex did not feel the same responsibility towards her. Now that she has HIV, she wants to take steps to protect her partner if she starts a new relationship. Pamela's desire to protect her partner points to the gendered notion of care- women are seen as caring for the wellbeing of other people yet men do not always share the same caring concerns for women, as I also noted from observations of men during testing and counselling sessions.

For many women living with HIV, sex and relationships are important issues yet these are issues that treatment organisations in this study have tended to overlook. The message from treatment providers have focused on women negotiating safe sex as part of living with HIV- here, providers assume that women can take control in negotiating condom use but in reality, it is difficult for women to do so. Negotiating condom use with a partner requires confidence and sensitivity yet in a society where there is great secrecy about sex and sexuality, I note from the experiences of women in this study as well as observations in counselling that it is generally difficult for women to talk to their partners about protection against sexually transmitted diseases. It is men who make decisions about sex, exert a great deal of pressure on women and expect not to be questioned about their decisions.

Despite messages from Christian churches to young people to abstain from premarital sex, the reality is that premarital and extramarital sexual relations are quite common in Northern Nigeria and it is not uncommon to find relationships that crosses intergenerational lines between older men and much younger women. Jordan (2005) has noted how the religious framing of the debate on HIV in Nigeria has centred around three key patterns of behaviour- abstinence, moral partnering and denial. Abstinence means refraining from sexual intercourse, moral partnering refers to the construction of a sexual relationship based on monogamy and religion whilst denial refers to sexual behaviour that is hidden away from society- this type of behaviour may be rationalised, hidden or denied altogether, similar to what I observed in the counselling session described in chapter [1.1.4](#) of this research. Whilst she did not explain fully the circumstances that led to her contracting HIV, Pamela told me that she was in a relationship where both partners promised to faithful to each other. Jordan (2005) notes that moral partnering is a common type of relationship among young people, framed within a religious discourse that involves faithfulness to only one partner at a time while forgoing other relationships. However, this increases young women's susceptibility to HIV because of the tendency to forgo consistent condom use in this type of relationship and it leaves women like Pamela struggling to negotiate safe sex and condom use. Pamela trusted her partner enough to stop using condoms but now that she is HIV positive, she struggles to rebuild her trust in men.

HIV had a positive impact on Pamela's spiritual life,

'It's not just easy. But sometimes, I get over it and I can be so much more that I will even tell God, 'oh God, thank you I'm positive.' It might sound stupid but I just feel that there is a reason and I strongly believe that the reason is not lamenting that will help but rather to cope with and life goes on.'

Through her belief in God, she recognises that she has to take control of her life now and she frames HIV in spiritual terms by stating that, *'I will even tell God, oh God, thank you that I'm HIV positive.'* This statement reflects Pamela's identity as a Christian woman. It speaks of her relationship with God and her attempts to make sense of HIV. She sees being positive as a form of redemption. For Pamela, redemption involved regaining her relationship with God back by abstaining from

sex; being thankful for being positive is Pamela's way of personalizing the meaning of HIV and bringing about a renewed appreciation for her Christian values. HIV has refocused Pamela's attention on what matters most to her- her spiritual life and herself. Personalization has enabled Pamela to achieve some equilibrium as she elaborates in her interview, *'I just feel that there is a reason and I strongly believe that the reason is not lamenting that will help but rather to cope with and life goes on.'*

Her statement here shows an attempt to situate HIV in her new identity because *'there is a reason'* for being positive. By moving on with HIV, she could preserve the spiritual and moral values that gives her meaning and enables her make sense of HIV. The statement also reflects Pamela's desire to leave her past behind and move onto the future but to do so, she had to rebuild her relationship with God and He had to be present in all areas of her life, including her relationship with men. She had not felt confident in negotiating her sexual life pre-diagnosis but now that she is positive, she feels empowered to practice sexual abstinence though she recognises that not all men would agree to abstain or use condoms and not all would agree to be involved in a relationship with her because of her HIV status. Pamela states that HIV had disrupted her life,

'sure, sure, it does but who am I to ask? I don't know, if I emmm say I would lament, I would keep asking questions. I will just hurt myself the more so I try my best to live in the midst of all that hurt and all that lamentation.'

She questions why she is positive but understands that there is really no point asking why because this would not solve anything and would not take away the HIV, however much she laments about it. Thinking too much about HIV would only hurt her.

Some months after the first interview, Pamela began a relationship but it is one that is fraught with uncertainty as she sees HIV as a threat due to her fear of stigma and rejection,

*'Yeah but not something so serious, I don't know (**hesitantly**). He knows my about my status and he is so much this kind of person that says he doesn't care and he really wants to put a smile on my face but sometimes, I have*

problems with his attitude as sometimes, I get confused whether its him or it's my condition so the truth is that if you are positive, little things well, even things that doesn't.... you are not supposed to think that way, you feel the person is behaving that way because he knows your status.... the fact that he loves me, knowing that I'm positive and he sticks by me, it's something to start with..'

Pamela feels that with HIV, her choice of partners is limited and as a result, she puts up with her current partner's non-committal behaviour, which leaves her feeling anxious and confused although she was not sure whether his lackadaisical attitude towards her had to do with her HIV status. But it left her feeling defensive and still prepared to put up with him because, *'the fact that he loves me, knowing that I'm positive and he sticks by me, it's something to start with.'* Pamela sees life through the lens of HIV- HIV is present in how Pamela sees herself and how she negotiates relationships with herself and with her world. She also frame HIV in terms of the medications that she has to take,

'I keep telling myself and my friends, it's not even the positivity that is my problem, the fact that every day after you wake up, you must take drugs morning, you must take drugs and in the evenings, every day of your life, you have to take drugs... I take them, it's just that I get tired.'

Pamela's statement that *'I take them, it's just that I get tired'* indicates that adhering to her medication is a challenging task. The side effects so severe that she sometimes skipped her medication. Pamela feels overwhelmed by her medication- first it is a reminder to her that she has HIV and secondly, she has to take her drugs every day, as she notes in her statement, *'every day of your life, you have to take drugs.'* Taking drugs is a daily burden from which there is no escaping and must be taken for the rest of one's life. She also speaks of her ongoing struggles to accepting her positive status,

'it might sound funny but it's because I strongly believe that in a matter of time, I will be negative. I don't know but I have that assurance.'

HIV has shattered her biography and her attempts to form an HIV identity is an ongoing struggle- HIV has constrained her life and limited her relationship options, leaving her struggling to move on with life as an HIV positive woman. At the same

time, she has sought to regain the moral ground through her relationship with God. She has never disclosed her HIV status due to her own fear of stigma and family opposition to public disclosure. Pamela fears that if she goes public to disclose her status, her family and friends could disown her.

Reflexive thoughts

Pamela was still dealing with the emotional impact of her status and I had to be careful not to blur the line between research and counselling. I stressed at all times a duty to protect her but on the other hand, I had to accept it was not really my responsibility to counsel her nor act as a carer for Pamela. She also found it difficult to take her drugs; whilst it was not my responsibility to force Pamela to take her drugs, I had to use my counselling skills to encourage her to visit an HIV specialist as I could see there were some issues with her treatment. The specialist recommended that Pamela should transfer her treatment from the clinic where she was receiving treatment as he felt she was not receiving the right treatment but he warned her that the clinic he was recommending has a large programme and she could meet people she may know. Pamela was paying a large sum of money for the same treatment that the other women in this study were receiving free of charge yet the private facility that she attends does not have the expertise required to treat HIV. Ultimately, it was Pamela's own decision on whether or not to take up this recommendation. Pamela was experiencing side effects with her medications, which made her nauseous and sick; neither was she eating properly. Pamela also struggled to take her drugs on time, did not know the names of these drugs though she could describe the size and colour of these drugs and was sometimes unwell. She disguises her illness by saying that she is a 'sickler', a term that is commonly applied to other illnesses in Nigeria including sickle cell anaemia.

Pamela was very keen on a relationship that would lead to marriage and she was prepared to put up with her current partner's nonchalant attitude even though she herself recognised that the relationship is full of uncertainty. This had an emotional impact on me as I was not sure that I could see myself putting up with such an attitude from a partner but I had to accept that it was not my place to tell Pamela how to conduct her relationships nor to judge her for it. Pamela was also struggling to cope with issues of rejection, as she had a relationship with a man who rejected her, once she had disclosed her status and this contributed to her lack of self-worth in her present relationship. She was also desperate for a cure too. Pamela refused to accept her HIV diagnosis, a stance, which bears some similarity to Irene's initial reaction to HIV.

6.5 'At times, I feel guilty'- Irene

Earlier in chapter 5.2.3 of this thesis, Irene spoke of the difficulty she had in coming to terms with her HIV status. She elaborates further on the impact of HIV on her life,

'you know on the negative side, on the negative side, at times I feel guilty.'

Irene talks about feeling guilty which she attributes to her HIV status. She feels that without HIV, she would have been able to achieve more life with her life. Irene's HIV status intensifies her feelings of shame because society looks down on people living with HIV and denies them opportunities,

'My prayer is that God should just take away shame off my life, that one I know. You know Nigerians, human beings entirely, not just even Nigerians, they will start looking down on you and all, and maybe you might lose that job because of your status whereas you are good at it [your job] and you are due for it, but because of your status and other things, the job will not be given to you.'

HIV is so shameful that it leaves Irene desperate for a cure,

'As of Monday, I went for another test again just on my own, I went for a test. Actually, I didn't tell them that I had HIV, just that I had a test last year, that I want to confirm myself again, with the high spirit in me that the result might be negative but then the outcome was still positive but I didn't, I wasn't angry with myself nor with God. I say, I know, one day there is going to be a cure.'

HIV made Irene feel guilty for being a woman with a sexually transmitted disease. Irene went on to marry her fiancé who was aware of her HIV status but the marriage has ended in divorce. Irene thinks that her HIV status was a contributory factor in her husband's decision to divorce a decade after they married. It also appears childlessness was another contributory factor to the divorce but Irene frames this through HIV. She refers to how HIV had an impact on her sexual relationship with her husband and they had to practice safe sex with condoms so that her husband would not contract HIV,

'let's be frank, when it comes to the sexual aspect, you know, at times, I get worried because even if I should have somebody that will admit me and maybe deep down within him, this person is like and I am going to be lying with the person, you know, am I not endangering myself? Am I not going to die? Because he might not have that boldness in me like the way I have that nothing will happen, I am going to live long, he might not be thinking that way, the way I'm thinking. At times, it gives me a cause to worry.'

Irene would have preferred a sexual relationship where there is love, intimacy and

trust despite HIV but condom use was a constant reminder to both Irene and her husband that she has HIV, a sexually transmitted disease and they needed to use condoms to protect her husband. Condom may have prevented the transmission of HIV but it acted as a barrier to the couple having children. One of the counsellors told me that during the early years of the epidemic, treatment providers advised PLWH not to have children, as they could potentially risk passing on the virus to their children. Condom use left Irene and her husband with unmet sexual needs and prevented the couple from achieving intimacy.

Condom use left Irene feeling guilty and worried that she could still infect her partner and in particular, it brought an emotional response through feelings of anxiety and fear that she was a risk to her former husband and she would remain a risk to potential future partners. Irene saw herself as dangerous and pathological- she wants to remarry but *'to have somebody that is going to marry me now, how am I going to disclose it, let's be frank, when it comes to the sexual aspect, you know, at times, I get worried.'* She fears that she would have to disclose her HIV status and she understood that this could leave her open to rejection by her partner. Even if he is still to accept her with her HIV status, there still remained the issue of sex, for which they must practice safe sex at all times to prevent the transmission of HIV. Irene's thinking here demonstrates that HIV is not just a physical ailment but one that also exists on an emotional level, as it creates guilt where there is a possibility of infecting another, particularly in the quest for a child who may turn out to be positive. She feels a sense of loss at not having a child as well as the loss of her marriage.

Irene is filled with regrets about her marriage and subsequent divorce yet it appears that she had experienced some form of abuse during her marriage that she was not prepared to discuss,

'One of my regrets is that why did I get married? I could have just stayed on my own; at least I would not have a spoiled name; let it be that I had discovered it myself and won't have had anything like marriage.'

Divorce gave her a *'spoiled name.'* Divorce is hard for women in Nigeria- it exposes them to ridicule and loss of social standing. In Nigeria, it is normal for families to intervene when there is marital discord between couples and a drama involving the

two families is played out to bring about reconciliation between the couple. If a wife leaves her marital home and returns to her parents' house, members of her husband's family might go to her family to plead for her to return to her marital home, thus strengthening the woman's position in her marital home, if she decides to return. In Irene's case however, this scenario did not happen, presumably because her husband was not interested in continuing with the marriage, as she narrated the story of a cousin who was also experiencing marital issues and had returned to her father's home,

'Thank God for your own, he will definitely come, now his relatives are coming to your house and his own is just maybe because of pride, that is making him not to come and beg but I know he will definitely come for you but my own, they didn't come. They [my family] sent for them [husband's family], none of them came, you can imagine my own. But your own at least, his relatives are there, they are coming, checking on you and I know, most of them, they might come, they might even drop some money for you but for my own, none of them have ever for once given me N1 for my upkeep. It is only me struggling on my own.'

Irene left her marital home empty-handed; her family tried to get in touch with her husband and his family to reconcile the couple but her husband failed to come; Irene feels that her HIV status was a factor in her husband's decision. Under Nigerian law, a divorced woman is entitled to an alimony from her spouse but Irene's husband failed to provide for her financially and Irene herself did not wish to pursue him through the courts. Just as significant for Irene is that fact that she does not have a child. A child would have made the marriage worthwhile but the end of her marriage without a child is one that fills her with regrets. Irene now regrets getting married. The end of her marriage has given Irene triple labels that she returned home to her parent with: HIV positive, childless and divorced. Irene feels that HIV could expose her to stigma if people in her wider community were to discover her HIV status,

'I was just imagining myself thinking, 'this thing again, if people should know about it, how am I going to live my life again?'

Social standing (i.e., how others see her) is important for Irene and she fears that she could be the subject of other people's gossip because of HIV. The fears and anxieties that Irene expresses about her HIV status are similar to those expressed by Rabi and Pamela who, like Irene, were concerned with protecting their moral and

social reputations by not disclosing their HIV status, despite the reported benefits of during so. Irene did not think she could live with people knowing of her HIV status and gossiping about her. Her fears of being the subject of gossip underlines a tension that exists between her healthy self and a potentially AIDS defining illness as she tested positive in 2003 and was asymptomatic until she fell ill with tuberculosis in 2012. She spent much of that year receiving treatment for TB and had to begin ART as well. Illness disrupted her life and her job was uncertain but once she began treatment, she recovered her health. As she has never disclosed her status beyond her family and her pastor, she feels ashamed that she could be the subject of gossip speculating about the true nature of her illness.

Irene is a very ambitious woman but she fears that her HIV status could have an impact on her employment prospects. She wants a better job with better pay and prospects but she expresses fear that she may not get the job she desires as companies often demand health tests even though this is illegal,

'shay I told you the last time, I'm trying to get a new job now, I don't know where I might find myself one day and I won't really know their rules, because you know in Nigeria now, if you go into any organisation, they will say you should bring medical certificate and other things. There are some that might allow you to go and bring it from your outside but there are some that might say they have their own people inside that they will do it inside so I don't know which one, I don't know where God is going to place me.'

Secrecy dominated Irene's experience of HIV, not only through non-disclosure but also through her medications. Irene describes her medication,

'honestly, it's a thorn on my skin. It's a question of keeping to time. The honest truth, I know once it's past 9, I don't take it- it is not every day that I take it exactly the time I have scheduled for myself that it is 8 in the night. But there are times I take it 10-15 minutes past time, sometimes up to 30 minutes past time. There are days I take it easy, 8 o'clock. It is a challenge, there are times I start taking it and I say, what? I'm tired of this thing.'

Irene further elaborates how taking drugs makes her feel and the taste and size of the drugs,

'I'm someone that don't like drugs. I feel it, like, am I a cow that will be taking drugs?' I was thinking it was bitter but then I try to like, zone my mind that I

will not feel the bitterness and actually, it wasn't bitter, it's not bitter. It's just the size of it, I don't like it, I don't like the size of the drugs, it is big.'

Taking her drugs requires effort and planning, particularly if she has to travel,

'I know anytime I'm going to travel, I try to like, for days I'm going to travel, take the drugs for those days I'm travelling and some extra. I will take an extra one because I might not know what might happen, I might not come back that very day that I have planned, so I will try to like, take two or one more extra for the days I've picked, just to see that I don't miss taking my drug.'

Irene took care with taking her drugs and storing them away from people,

'actually the container they gave us at the clinic, I try to like, share it into two because I don't leave the container just opened like in my room because some people just come in like that into my room. So there is a container which I have, it was a vitamin C container that my dad used, so I now decided to take the container so at times, I just decided to take, lets say 20 pieces and then put inside the container then keep it on my cabinet in the room. When you see, you might not even know what it is.'

The medication that Irene takes every day is the most visible sign of HIV, so she has gone great lengths to conceal them, including splitting them into different containers and hiding them away from others and similar to Ella, she finds taking her medication challenging. At Irene's treatment provider, staff warned patients about the dangers of removing labels from their drugs or putting drugs into containers with labels for another type of medication but Irene's desire to keep her HIV status secret led her to take measures that went against these warnings. She was aware that people could enter her room without her permission, so she stored some of her medication in a vitamin container so that they would not know that these are HIV drugs and she did not consider the possibility that people could help themselves to the drugs without realizing they are for HIV. The size of the drugs is another visible reminder to Irene of her HIV status and taking them makes her feel like 'a cow' who needs pharmacological help to stay alive. Taking these drugs 'is a thorn' but they keep her alive and healthy. She did not always take her drugs on time and constantly has to remind herself to do so. Irene finds it a challenge taking her medication at the appointed time. At Irene's treatment provider, staff recommended that patients should set daily alarms to remind them to take their drugs,

'I don't because I know I have scheduled it so that it's 8 every night.'

As an alarm is a clear, visible and loud reminder of one's illness status, Irene has refused to use an alarm. Perhaps, this is not surprising because in Nigeria, there is a common belief that when someone relies on alarms to set reminders for their medication and if they take medication at night, then the person must be HIV positive, so Irene also took care to take her drugs secretly, away from prying eyes. Travelling presents unique challenges that requires Irene to plan her medication schedule ahead if she needs to travel.

6.6 'Will I get a husband again? Can I have another child?'- Binta

Binta is a widow who tested positive for HIV in 2012 after discovering her husband's medication and confronting him about them. Binta reflected on how her husband's chronic illness disrupted their lives as she struggled to take care of him on her own. Despite her anger at her husband for infecting her, Binta was prepared to stay and care for him. Binta's decision to continue with her marriage points to a gendered experience of HIV and marriage. In Nigeria, society tells women that marriage is something that a woman has to endure, even if she is not happy. Binta however made it clear that it was her own decision to remain in her marriage and together with her husband, agreed to keep their HIV status a secret,

'my husband and I took the decision that we would continue staying together and we will keep it secret between us'

Secrecy was an attempt to protect themselves and in particular, her husband, from gossip and stigma about his health status but it also made life difficult for the couple by isolating them from potentially supportive networks of family and friends. Keeping their HIV status secret also placed a heavy burden on Binta and put her at a disadvantage, as later events would demonstrate. Moreover, the couple's attempt to live a 'normal' life and maintain their secrecy was disrupted by her husband's illness episode, which made it difficult for Binta and her husband to keep their HIV status secret,

'He fell sick, he fell so sick and he was admitted to the hospital.'

The gendered nature of HIV is apparent in Binta's account- her statement that *'he fell so sick'* points to the months of challenges caring for her husband and her own HIV status became a secondary concern, as she looked after her husband. Binta's husband ended up on admission in hospital. It was during his final stay in hospital that her husband's family became aware of his HIV status and he divorced her in the Islamic prescribed manner by simply uttering the words, 'I divorce you' three times, despite Binta's pleas to her husband not to divorce her. Once he divorced her, his family cut Binta off and she never saw him again until he died. Binta's in-laws blamed her for infecting him but Binta was unable to refute their accusations because her husband never told his own family about his infection and divorcing Binta implied to his family that he had contracted HIV from her. Binta is however clear about the source of her infection. Talking about her diagnosis is a painful chapter in her life,

'wow, it is one of those things I don't just like discussing because it is a painful part of my life but since I have decided to talk to you, I will tell you. Well basically, I got my virus through marriage, so emmmmm, my husband was sick and we keep taking him to hospital with no responses. Later, we parted ways as couple so we just came back together and reunited. I was just cleaning the house, emmmm, then I came across drugs placed in one of our chairs....under the chair so I picked it up and untied the cover he kept it inside, so I was like, what is this? So while I was trying to find out what drugs is that because since it is only me and my husband at home, so who could have kept that? I told my husband and ask, 'what are you doing with that?' Oh, that's my own drugs.' While I am married to you I was like, it looks suspicious, why is it here? That's what I told him. He said, emmm, 'no, I wanted to go and dispose of them because they have expired.... I asked him, is there something you are not telling me? He said no. My body and my conscious say he is hiding something, I guess maybe because of the nature of Nigerian movies I watch. Sometimes, in Nigerian movies when you see movies about AIDS, you come across stories with containers for ARVs. I just turned to ask him, 'are these ARVs?' My heart is telling me they are ARVs. I have never seen ARVs with my naked eyes. He say, 'no, they are not.' So I just went into the room to get a cover to close one of the drugs. When I turned, to my surprise, the man was kneeling on his knees. I burst into tears, crying. I say, 'why did you marry if you know you are sick?' He tried to explain. To cut a long story short, we cried all day together. We drew close.'

Binta's experience with her husband bears some similarities to that of Halima and Rabi whose husbands had started taking HIV medication without informing their spouses of their status, leaving them open to infection. Unlike Halima and Rabi

however, Binta found her husband's medication and was able to confront him while he was still alive. Even though her husband tried to assure her that there is a possibility that she might still be negative, Binta knew that she had to take an HIV test so that she could know her own status. From the beginning, Binta has stressed that, *'I got my virus through marriage.'* Contracting HIV through marriage helps her to resist the stigmatising effects of an HIV diagnosis. When she first discovered her husband's hidden medication, she instinctively knew that something was not right and her husband was hiding his medication. She could not understand why her husband was keeping secrets from her. Even though she had never seen ARVS, she knew from her knowledge of Nigerian movies and media information what the drugs were for. The experiences of women like Rabi and Binta demonstrates that Nigerian movies are a useful medium in educating women about HIV, since these movies often mirror the realities of Nigerian society.

During the early years of the HIV/AIDS epidemic in Nigeria, attempts to reduce the spread of AIDS focused on behavioural change, with many of these messages tied to religious-based abstinence messages which targeted women. The focus on behavioural change failed to halt the epidemic but Nigeria's film industry has been more successful in highlighting HIV/AIDS issues as a way of educating people about HIV/AIDS. Binta cites Nigerian movies with improving her knowledge of HIV; through the movies that she has watched, Binta understood that her husband had deliberately hidden his HIV status from her. Binta says of her relationship with her husband when she confronted him, *'we drew close'* but in reality, her husband's failure to disclose his HIV status left her feeling very angry and betrayed and there were further arguments between the couple over this, as her husband later tried to justify his reasons for hiding his medication,

'he even say he personally kept the drugs there because he knew I was going to see them and I would come across them. I told him that 'you were hiding it. How on earth would you think I would go and see that place? That is under the chair we are talking about.'

Binta says she knew she was at risk at HIV because,

'I have already known that the man I called my husband, the man I sleep with unprotected every night is and I know one of the ways to get infected is through sexual contact.'

Once she and her husband decided to remain together, her husband's condition deteriorated rapidly. Binta described the months of caring for her husband alone in their home and some of the unpleasant manifestations of HIV/AIDS illness she saw in her husband, including diarrhoea and how his mental health deteriorated. Those months were also financially draining too, not least because her husband was duped by a fraudster who conned him out of a fortune by claiming he could cure him of AIDS through 'blood cleansing.' Binta's husband spent the final months of his life in hospital and when his family discovered that he was dying of AIDS, they closed ranks on Binta, pointing accusing fingers at her. His family did not acknowledge the months she spent caring for him and her loyalty to him; it was easier for his family members to blame Binta for infecting him and then keeping the infection secret from them. As was the case with some of the other participants in the research, Binta was held to a higher moral standard than her husband was. Men are not expected to give account of their infidelities, even if they infect their wives with sexually transmitted diseases. Binta didn't confront her husband about HIV itself but with not informing her of his HIV status by hiding his medications from her and infecting her.

As a divorcee and a widow, Binta often thinks about her future life in the light of HIV,

'Well, yes, will I get a husband again? Can I have another child? From where? All these questions come to my mind. Will my life be normal like any other person? How long can I live without getting or falling sick? Because I'm healthy now, I don't have challenges but you know, people with our type of situation face the challenge of sickness and others.'

In this particular aspect of Binta's interview, two identities that are important to her are highlighted here- she wants to remarry and be a wife again and she wants to have another child and be a mother to children. These are socially expected roles. However, HIV disrupted Binta's expectations. She found herself questioning whether she would ever remarry or have more children again. HIV affected her identity in ways that led her into thinking about herself and what the future would hold for her. HIV added an element to her identity by positioning her as an HIV positive divorcee whose husband passed away from AIDS. How could she begin to explain herself to potential suitors? Would they still be interested in marrying her knowing that she has HIV? Would her *'life be normal like any other person?'*

Her reference to *'our type of situation'* suggest that she sees HIV as unique because it brings challenges such as stigma and illness and it dehumanizes her by making her feel that she is not *'normal.'* Binta was also worried about her health. Although her CD4 was high and she remained healthy, she nevertheless feared progression to HIV illness. She understands that her health status could change in future and that she could not control the course and progression of HIV. Binta feels that marriage and pregnancy would make her feel *'normal'* again and remove the emotional pain she feels from living with HIV.

Binta has not disclosed her HIV status to her friends because,

'I don't want them to desert me. I don't want publicity. I don't want sympathy...most of our people are still not so educated on this illness, so I don't want somebody seeing me like a dead person.'

Binta has never disclosed her status because of stigma. Due to widespread misconceptions about HIV, Binta has not disclosed her status because to do so leaves her at risk of exclusion and rejection by others. Binta wants to be treated with dignity and respect; she wants to live with HIV on her terms even though being HIV positive is not something that she desires. Disclosure is not an option because it would be tantamount to social death.

In chapter 6.2 of this thesis, another participant, Rabi spoke of how her society views HIV positive women, something that Binta also echoes but in contrast to Rabi who has decided that she would no longer pursue relationships with the opposite sex, Binta admitted that she would like to have a man in her life. She want sex, companionship and friendship but expresses anxiety that suitors could reject her because she is HIV positive,

'I used to tell myself, don't try it because I might end up getting hurt or getting involved with somebody that might end up knowing your status and dumping you is one of the things that I try to get away from.'

During the first interview, Binta admitted that she has met a man who has proposed marriage and she is anxious about disclosing her status, as she fears that he could reject her because of her HIV status. Her suitor has made it clear that before proceeding with the marriage, they would have to take an HIV test together and

Binta does not know how he will react if he finds out that she has already tested positive.

Binta had previously scandalized her family by having a child out of wedlock and it caused tensions between her and her family. In Nigeria, women are subject to a gendered double standard of sexual morality in a way that men are not and women who do not conform to cultural norms regarding sexual morality run the risk of being labelled as wayward women. In chapter 6.2 of this thesis, Rabi refers to how society associates sex, gender and HIV when she stated that, *'it is something that they understand or come to think that if you are HIV positive, most especially the women, automatically, you are a prostitute.'* Northern Nigeria is a society with patriarchal tendencies where women are regarded as subordinate to men; women are traditionally seen as wives and mothers and they are expected to reflect these roles through marriage and childbearing. Marriage and childbearing are seen as both *social* and *religious* duties. Remarriage is therefore not a choice but a necessity in a society where an unmarried woman has no social value. As a result, Binta feels that she has not fully fulfilled her goals in life. This is why she asked, *'will I get a husband again? Can I have another child? From where?'* For Binta, there were no easy answers to these questions.

6.7 'I just want to end it, that made me decided to kill myself'- Grace

Perhaps more than all the other participants, HIV had the most profound impact on Grace's life. Grace describes herself in the first interview,

'I can tell you that I'm an HIV positive person. I met this sickness in 2007. I went for check up in the hospital. They test me and they find out that I'm positive.'

The impact of HIV is apparent in Grace's life. Grace frames HIV in terms of the multiple losses that she had experienced when talking about the impact of HIV on her life; HIV had an enormous impact on her psychological wellbeing, which culminated in her attempting suicide. HIV/AIDS also disrupted Grace's life trajectory through the deaths of her parents,

'I know my parents die with HIV, both my mother and my father. When they died with it, there was no medicine.'

HIV has left no aspect of Grace's life untouched. It changed the nature of her relationship with her mother as she went from being a child to becoming her mother's carer. Grace had to drop out of school and was forced to grow up quickly and assume responsibilities that left her emotionally distressed, as she did not understand the nature of her mother's illness but she knew it was an illness that brought severe pain and suffering to her mother,

'I was taking care of her. She really suffered.'

Looking after her mother was very stressful for Grace. She and her siblings experienced humiliating gossip from neighbours,

'But that time then, we were just hearing it in the village that she has positive but she didn't open her mouth and tell us that this is what is disturbing her. We are hearing our people, our people outside there they are telling us that our mother is HIV, that is why she is suffering like this. But let her tell us what she is suffering, she didn't tell us. But she really suffered. She even died in my hand. She died in my hand but she really suffered before she died. So nobody has ever given us a teaching about this is how HIV is going on.'

The gossip Grace and her family experienced from their neighbours was bad enough but Grace's statement that her mother, *'But let her tell us what she is suffering, she didn't tell us'* suggests that she still feels angry with her mother for not telling her about HIV and preparing her for her (mother's) illness and death. Grace's anger towards her mother intensified, as she herself later tested positive for HIV, likely because she failed to take precautions to protect herself when she was taking care of her mother, as she was unaware of the nature of her mother's illness. The possibility that her mother might have been too embarrassed to tell Grace about her HIV status is not one that Grace has considered. Nigerian parents and mothers in particular, are generally not comfortable discussing their health issues with their children, especially one that involves a stigmatized condition that is considered as a sexually transmitted disease. To give an example from this study, Ria has told her

child that she has HIV but she has not spoken about it in depth with her child, as she still sees him as a child whom she has to protect,

'he knows that I am positive. But you know the knowledge of HIV now for him, he doesn't know it very well.'

There are constant reminders of the losses that Grace has experienced as a result of HIV, particularly in relation a lack of a cohesive family unit, which led to feelings of loss intensified by her perception that her friends have a strong family unit, something that she does not have,

'Like me, I keep comparing; I go to my friends' houses, I see them, my friends playing with their parents, you understand? When they play with their brothers, you understand? You see brothers and sister, you understand? You see them very close, they are doing their things together, you see the parents' marriage, see how they are very organised.'

After Grace's mother died, Grace and her siblings were sent off to live with different relatives and this exacerbated Grace's feelings of loss. Family is at the very root of Grace's identity; being part of a family gave her structure, protection, meaning and a sense of belonging but with her parents' deaths, this option was taken from her. Grace was particularly bitter about separation from her siblings, as she feels that being with her siblings would have helped them grieve together and they would have been able to give each other the emotional and psychological support they needed in coming to terms with their parents' death and she also acutely feels the loss of her parents,

'when you see your own, your parents are not there, you ma see the way you remember, like me, when my father died, they decided to, you understand, everybody come and pick one, we are four, so we are not in one place like four'

Grace's father's relatives did not give Grace and her siblings the opportunity to make their own decisions about their living arrangements even though these same relatives were largely absent from the picture when Grace's mother was dying. The absence of relatives during Grace's mother's illness is quite striking- this reflects how much the HIV/AIDS epidemic changed social and familial relationships. In the past,

relatives rallied around to look after other family members but the HIV/AIDS epidemic has strained the capacity of families to look after each other. Grace's father's relatives had already left the family destitute by taking her father's properties away, leaving her mother with no inheritance from her husband- in Nigeria, it is quite common for a man's relatives to take away his properties after his death, leaving his widow and children destitute. Grace's statement that *'I was taking care of her'* testifies to the absence of relatives during her mother's illness and the lack of support from them. These relatives took the decision to split the family and sent Grace and her siblings to live with different relatives. Grace and her siblings had to wait until they were adults before they could rebuild their relationship with one another.

The home of the relative Grace went to stay with after her mother's death was not a happy one and Grace experienced panic attacks and a loss of confidence, as she was mistreated by her aunt,

'sometimes, if I'm hearing her noise from the far if she is coming, then I will just tense because of the way she behave to me. She will be talking to me, she will be shouting at me, you know, when somebody is shouting at you, you will never have the confidence to do or think..... you know, so from far, if I hear her voice, I will start panicking. The time she is supposed to come home, I just look at the time, my heart will be start beating.'

She felt no sense of belonging in living with her relatives and was desperate to leave but she could only do so through marriage. Grace thought that with marriage, she could regain a sense of belonging with her husband and through having children, which would in turn create a new identity for her as a wife and mother. Grace met and moved in with the man who became the father of her child although they never formalized the relationship; despite this, Grace called described this relationship as a marriage. During Grace's pregnancy however, her partner's attitude toward her changed and the relationship changed,

'as I tell you earlier, I married the father of my son, we are happily. We lived as a happily home, we are living very well but once the sickness started bringing me down because you know when you are pregnant, you are taking drugs, even the drugs they give you in the hospital, you find so difficult to take the HIV medicine, so I'm finding it so difficult to take it and you know, when

you have pregnancy and you are HIV.'

Grace experienced a difficult pregnancy and had to start taking HIV medication. It appears that the medication brought a new dimension into the relationship, as it was the most visible sign of Grace's HIV status. Her partner abused her physically and emotionally, with Grace attributing her HIV status as a factor in this cycle of domestic violence,

'he know I have this sickness and say we should go ahead and marry ourselves. After the marriage passed on, he now started messing me, that I'm HIV positive, 'I won't marry you', I should go and live with my sickness with my people, so that he is not going to marry me again. I was four months pregnant. He took me to my parents in December 2010. He took me back on the 23rd'

The fact that Grace mentioned the date the relationship ended shows that it was a very painful event for her. Grace was hurt by her partner's attitude and his rejection of her and their unborn baby. She experienced this rejection as stigma because prior to this event, he had refused to provide money for feeding, due she thought, to her HIV status. Grace felt that he had used her and dump and she was very upset, as she explained that she had been honest with him from the beginning about her HIV status,

'And he knows I've it because before we go with the relationship, I asked him for a test, let us go and do a test so that we should know our stand.'

Grace had nowhere else to go to- her partner sent her packing back to the relatives she previously lived with and it was whilst living with them that she gave birth to her child; her aunt was not happy at having Grace back home.

Grace is an active member of her church but the pastors suspended her for not formalizing her relationship with the father of her child in the church,

'I open up to tell them is that this is what is disturbing me is, you know when I get married to the father of my baby, I didn't do a church wedding. You know

in COCIN¹⁶, ECWA¹⁷, Baptist, once if you didn't church wedding and you are a baptising member, they will put you under suspension, they will put you under the sin, you will not be taking holy communion, doing anything you know, you will not be participating, you know.'

The suspension occurred when Grace was still pregnant and it was hard for her because it took her away from the support she needed. She could no longer attend church services nor participate in church activities and she was socially isolated from other members of the Christian community. Grace felt the pain of the exclusion that was imposed on her by a patriarchal church. Before the church lifted the suspension, Grace told her church what had transpired between her and her partner, something she felt she had to do with because she thought she would soon die as she experienced severe illness during pregnancy,

'I was thinking maybe I was going to die, I didn't know I was going to live, so when I went there, I was confessing and I now tell them that it is the father of my baby did to me because I'm HIV+; they now asked me that didn't I tell him? I told him, we even went for a test before starting the relationship and he say he want to continue the relationship but later on, he now told me that he is not going to continue and I should go with my parents.'

The church forced Grace to 'confess' everything including her HIV status and the fact that she had been in a relationship with a man she was not married to and was having a child out of wedlock. They questioned whether she had told her partner about her HIV status, implying that he ended the relationship because she had not been honest enough with him. Given that the church is an important mediator in dispute between couples, at no point did the church offer to mediate between Grace and her partner. The church put the onus on Grace to prove that she had done nothing wrong. Grace was suspended from church and excluded from church activities during her suspension but her partner was never questioned once about his actions.

A painful aspect of HIV relates to her medication- Grace experienced survivor guilt when she began to take medication, as she relived the memories of her parents

¹⁶ COCIN- Church of Christ in Nigeria

¹⁷ ECWA- Evangelical Church Winning All

dying of AIDS. Unlike them, she has access to medication which was prolonging her life and helping to minimise the debilitating effects of HIV illness,

I know my parents die with HIV, both my mother and my father. When they died with it, there was no medicine. But we thank God that we have the medicine.'

HIV has shattered Grace's sense of identity and being diagnosed positive herself came as a blow to her self-concept, as she associated HIV/AIDS with the suffering and death she witnessed from her parents' experience,

'I didn't find it easy. I'm thinking that that is the end of the world. I'm thinking maybe tomorrow, I may die. That very moment, I'm thinking that's the end of my life.'

The stress of her own HIV diagnosis, the separation from her siblings, the breakdown of her relationship with the father of her child and the experience of being suspended from church was so much for Grace that she attempted suicide,

so sometimes if I think of all these, you understand? And the thing really disturb me, sometimes if I just look at it, my mind is going everywhere, I feel like just like me, I will just die. It's now my mind is not thinking of these things much but sometimes, I just want to end it. That made me decided to kill myself. When I think I took my medicine, almost 20, I swallowed them all, put it in my mouth; my friend came in time, so he put palm oil, he called one of his friends and they put palm oil in my mouth and I now vomit it.'

She also feels frustrated by what she sees as a lack of progress in life due to her lack of education (she only stopped her education at junior secondary level). Life was bleak, stressful and difficult and she admits crying whenever she thinks of her parents, particularly her mother. Grace feels that she has missed out not only on education but also on a coherent family unit, a feeling that intensifies whenever she visits friends and sees how united the family unit is, with a father and mother and their children. Nevertheless, she wants to move on with her life and she articulates her plans for the future and a desire to progress to higher education in order to get a better job and make a better life for herself and her child,

'I want to be something that I'm going to help so people the way I suffer in this life, I want to do something; I want to go back to school.'

Her worries and frustration stemming from the perceived failure to achieve anything in life has left Grace battling with anger, which in turn continues to give her headaches. The emotional, psychological and physical stress of living with HIV led Grace to take an overdose but her current partner rescued her just in time.

Reflexive thoughts

It was clear that Grace required professional help that was beyond the capacity of her treatment unit whose counselling unit was limited to basic HIV testing and counselling to help people find out their HIV status and start medical treatment, something that Grace herself is aware of. She did not feel comfortable discussing her personal issues with her treatment centre because she feels the treatment unit is too small and she knows people there. Grace complained of constant headaches and I had to ask her what she thinks might be causing these. She admitted it could be any number of things. I wanted her to bring up these issues herself and to enable her take the initiative herself in addressing them. She thinks her headaches may be the result of stress and repeated negative thinking. Her answers demonstrated the need for specialised psychological counselling which her treatment provider could not provide. With permission from Grace, I contacted a psychologist who specialises in counselling PLWH and she agreed to provide free counselling sessions to Grace for as long as she wanted and I passed her details to Grace to contact the psychologist.

I took care with Grace, ensuring that she understood that she has the right to withdraw from the study and has the right not to answer any question that she finds upsetting. I warned her that some of the questions could be distressing. Grace saw her participation in my study as a chance to talk about herself and her experiences of HIV- indeed, Grace was desperate to talk. I took care to ask Grace for consent prior to our interviews and I reminded her that formal interviews would be taped. She admitted that our interviews was the first time she has ever had the opportunity to discuss her life and her past experiences with her parents' illness. Confidentiality issues arising from the consent forms signed with the participants meant that I could not discuss Grace's problems with her treatment provider. Grace herself was not ready to join a support group.

6.8 Summary of theme two: the impact and meaning of HIV

The availability of treatment for HIV has enabled the participants to manage their lives in living with HIV. Although medication has improved their health outcomes, the

reality of life for the majority of the participants is that HIV is still considered to be an exceptional illness. HIV affects most aspects of the participants' lives in many ways that are not acknowledged by treatment providers and counsellors. HIV has affected the psychological wellbeing of most participants. Many of the participants viewed themselves through magnifying lenses that were dominated by HIV- this altered how they related to themselves, their bodies and their relationships with others. The women are also impacted by the negative social constriction of HIV as a sexually transmitted disease, which appears to play a role in how participants present themselves to the wider world.

Key themes that could be drawn out from the participants' account of HIV includes the experience of stigma, perceptions of their sexuality/femininity and the ability to control the course of one's life. Marital status had an impact on the participants' sense of self and their perceptions of stigma in living with HIV- married women, with one exception (Tlatu) cited their marriage as the basis for contracting HIV, an option that is not available to single women. More married women than unmarried women have disclosed their status and participate in support group meetings. Unmarried women, on the other hand, felt that they had experienced a loss of a future self because HIV has disrupted their plans for marriage and motherhood, which could have given them an identity and status in their society.

In this section of the thesis, participants revealed that they are keen to have some control over their live with HIV including their health and psycho-emotional wellbeing and medications. Some participants described how their ARVs remains a constant reminder of their HIV status but they also understood that ARVs was important and life-sustaining. Without ARVS, their lifespan would be shorter and they would be at risk of opportunistic illnesses. The women particularly appreciated the way ARV enabled them to regain their health, which went some ways towards boosting their self-esteem and enabling them to show others that they are healthy. But there was also a sense that their lives will never be normal. HIV remains a gendered experience for women living with HIV.

Chapter Seven: Theme three: disrupted lives, ‘repaired biographies’ Overview

In this overarching theme, the participants discussed their lives with HIV/AIDS and the attempt to repair their life biographies in moving forward through the mobilisation of resources. Among the themes that emerged are issues of disclosure, coping strategies, support networks and spirituality. This theme particularly resonates with Bury (1982)’s third point of biographical disruption: that it involves the mobilisation of resources to live with chronic illness. In this chapter, participants describe the resources they mobilised in living with HIV.

7.1 ‘The way I was before is not the way I am now- Ria

Ria emphasized the importance of her religious belief in sustaining her spiritually and mentally and her hopes for a different future. When she was first diagnosed with HIV, Ria was initially unsure of her life trajectory. Her HIV diagnosis at first shook her faith in God and left her questioning why she is positive and her question went to the very root of her identity as a wife and mother. Ria emphasized how she remained faithful to her husband even after he abandoned her,

‘One I’m not flirting, two since my husband left me, I have not been meeting men but this man came back and met me and I took in with my baby, they now tested me as HIV+, why should it be so? Why should it be so?’

HIV shattered Ria’s self-worth and her fear of being stigmatised as a result of her HIV status left her feeling worthless. She thought that she would soon die,

‘in those days, I was thinking that I will die o. I was thinking that I have nothing, that I am not important in society that was how I thought of myself.’

She attributes this lack of self-worth to lack of understanding of HIV and her initial shame,

'it's because of denial, when I was not educated of the knowledge, so I was lack of the knowledge of HIV, I refused to come out, I denied, I say I am not HIV positive, I was telling them that the result was not mine.'

Ria was at first in denial but the longer she has lived with HIV and with access to counselling and medication, she has been able to reconcile herself to HIV and to a stronger relationship with God. She sees God as being in control of her HIV and ultimately, her life; through her relationship with God, she has gained a sense of relief and hope in acknowledging that her destiny is in God's Hand and there is nothing she can do about this other than to develop positive coping strategies to manage life with HIV,

'Well, I thank God because God has been seeing me through the little work I'm doing.'

She ascribes spiritual meaning to living with HIV,

'Being positive for me means live a life to glorify God.'

Participating in my research was an opportunity for self-reflection for Ria and she was able to reflect on how living longer with HIV has strengthened her belief in God and increased her sense of worth,

'these questions that you asked me, it makes me to review the past and weigh it with the present now. The way I was before is not the way I am now. The way I stand firm in the Lord is not the way I stand before; before one leg was outside, the other leg was in but now today, I will teach and mix in the land of the living till the day that I die, till when my time is over that one day, one day, some day, I will be no more existing here on earth but I will go where the Lord has prepared a better mansion for me. One day, that is my heart's desire, I'm just praying for that day.'

Ria's experience of HIV is filled with ironies- it was her church pastor who advised her and her husband to reconcile and when Ria tried to negotiate safe sex with her husband, the same pastor (together with Ria's husband) silenced her by telling her that it was a woman's duty to fulfil her conjugal duties to her husband. At the time Ria tested positive, churches were preaching about sex and HIV and little was said about married women protecting themselves from sexually transmitted diseases, if

their husbands have had other sexual partners and some churches even actively discouraged condom use among their members. Ria nevertheless understood about sexually transmitted diseases and knew that condom offered some protection, yet her husband and church overrode these concerns. Now that she is living with HIV, it is to the same church she has turned to for help in coming to terms with HIV. Ria does not blame her church for acquiring HIV.

HIV changed Ria's life, her plans and her assumptions about her future. She understands that with treatment, she could continue living her life. Coming to terms with her HIV status was a gradual process, which began with forgiving her husband for infecting her. Forgiveness was a process which enabled Ria to gain a sense of liberation and control over her life with HIV,

'Right from day one, when my husband called me when I took in, I say I have forgiven him.'

By regaining control of her life, Ria achieved a sense of optimism about her future because in the same year her husband passed away, Ria began to receive free ARV treatment and she also obtained employment at the same treatment unit where she receives treatment. Part of the condition for employment is public disclosure- Ria had to disclose and live openly with HIV so that she could help others. Ria found disclosure of her HIV status quite beneficial,

'it prepared me to have that boldness to speak out. It prepared me by removing fears that I was having in my mind because to me, I was thinking that everything is fine.'

Ria found that the disclosure of her HIV status boosted her self-confidence and her work gives her a sense of purpose and meaning in living with HIV- it provides her with the opportunity to receive a monthly pay, meet and interact with new patients who are enrolling for treatment and it enables her to play a role in the wider HIV/AIDS community,

'I like chatting with the patient when he comes in, to sit and laugh with him, to tell him about my testimony so that he will feel at home because by the time that I open up to somebody anytime he comes, he will say, where is that

madam Ria? Why because I told him that the shoe that he wears, I wear it before him, so I'm still living by the Grace of God.'

Ria finds talking about her HIV status with others in the community therapeutic. Ria uses the word 'shoe' to describe herself to new patients to show that she understands what they are going through because she has been there herself. Ria feels that her work as a volunteer is useful and the fact that patients seek her out has increased her sense of self-worth, as she feels that her contribution to the HIV community is acknowledged. This in turn gives her a status as a valuable member of two communities that she identifies with- her clinic and her church. When new patients come to enrol for treatment, they interact with Ria knowing that she faces and understands the same daily realities that they also experience. Ria is also responsible for co-ordinating support group activities within her treatment unit. Ria's work as a volunteer provided an important platform for subsequent disclosure to her members of her church,

'it was during night vigil, they say everybody should bring testimony, so the way I disclosed my status is when I was giving the testimony about my state. I told them about who I am, how I became a Christian, how I got married, how my husband went and died and left me with the children. This is the condition I find myself since that 2006. I'm still living, so I tell them, 'if I didn't tell you people that I'm HIV+, nobody will know.' From there, everybody was looking at me.'

Ria's disclosure took the form of a testimony about her journey with HIV, as a testimony of her faith in God. It was also an opportunity for Ria to educate her church members about HIV and at the same time, to inspire hope and confidence in encouraging other people to disclose their HIV status. She ascribed a spiritual meaning to her disclosure and she alludes the the ,

'I say if I hide it to human beings, I didn't hide it to God, God knows my status and He knows who I am, I just want to build confidence to people that is why I was giving the testimony and to appreciate God for what He has been doing to me despite the fact that since 2002, they tested me as HIV+, I'm still living.'

Ria's decision to disclose her status elevated her in the eyes of clients at her clinic, her support group and her church as she was no longer just a widow and a mother but also someone with an important role in play in society as an HIV/AIDS activist and a leader in her church group. She became a public personality who is somewhat defined by her HIV status. Disclosure has not alleviated Ria's financial problems though she has insisted that her motivation was not for financial gain but to give thanks to God for keeping her alive.

Ria's leadership roles in the church and at her treatment provider have given her the confidence that she would probably never have had had she not been HIV positive. By contributing to her society, Ria feels appreciated and relevant which in turn has enabled her to incorporate HIV into her life trajectory. She has also reflected upon existential issues,

'one day, some day, I will be no more existing here on earth but I will go where the Lord has prepared a better mansion for me.'

She is no longer afraid of death because she believes that God has planned a better future for her in heaven. She speaks of her hopes for a better future because her biggest challenge is no longer HIV as she has already worked it into her biography but financial insecurity which left her worrying about her rent and looking after her children. Her main concerns as my fieldwork drew to a close was how her children would cope in the event of her death and she was also making plans to go back to school for further studies.

7.2 'I say nothing, I will thank God for my life, that's what I told them'- Maimuna

Maimuna was diagnosed with in 2003 after a long period of illness that lasted several months following her husband's death from an AIDS-related illness. Some of the symptoms, which were so distressing that they disrupted her life, came one after another,

'Before I had TB, I had eight boils in my private parts, eight of them came out, my mouth peeled right into my mouth, when I coughed, there was something coming out like milk, something coming out, very thick and I started coughing, from evening till daybreak. I will be coughing, I would sleep and wake, coughing till daybreak before the cough will stop. My body was shaking, I will be having fever, my body will be hot. My mother was taking water, soaking the water with towel and cleaning me to cool me. The towel will even be hot, they will change it to a cooler towel and even then, that towel will be hot, till daybreak they will doing this. They were putting towel on my body and on my head, those were my experience of the symptoms three months before they took me to Kaduna [translated Pidgin English-Hausa text]'

Maimuna's illness disrupted her life and it was obviously distressing for her. She was first treated for TB and when that treatment failed, her doctor advised her to take an HIV test. Maimuna went for an HIV test and the counsellor requested that she should return with a relative who sat with her through the counselling process, which seems to underline her lowly status as a woman. She does not have formal education and English is not her first language. It seems that the counsellor, who was a man, did not modify the counselling session to take into account Maimuna's level of understanding of what HIV means, so that she could have an individual counselling session. For Maimuna, the testing and counselling that took place reinforced the gender inequalities that women face in Northern Nigerian society. Despite her lack of education, Maimuna understands that HIV brings stigma and perception that HIV positive women are promiscuous. Yet the counsellor who told her that she has tested positive did not appreciate that Maimuna is an individual in her own right who can articulate herself, particularly in her own native language.

Structural inequalities and gendered experiences manifested in Maimuna's experience of HIV- she was unable to challenge her husband about his illness when he was alive and once he passed away, Maimuna was left to pick up the pieces, without financial nor psychological support from her husband's family and her gender meant that she was unable to challenge them for not telling her about the nature of her husband's illness. Maimuna had looked after her husband yet neither him nor his family members who were aware of the nature of his illness informed Maimuna until after his death and only after she had herself tested positive.

When Maimuna went for an HIV test and was informed that she had tested positive, she was very afraid. In the early 2000s, as Nigerians were becoming more aware about HIV, the societal view of HIV was defined by fear- it was seen as a devastating disease that leads to death- with HIV, people confronted their own mortality. But just as profound was the experience of stigma, as Maimuna articulates in her account of HIV at the time she was diagnosed,

'That time, people dey say anybody get this sickness, everybody go dey run leave am.'

[that time, people used to say they would avoid anybody with this sickness]

Maimuna is aware that HIV exposes people to stigma and she was afraid that people in her community would reject her if they were to find out that she has HIV. At time Maimuna tested positive for HIV, stigma was a major problem that PLWH encountered and was quite widespread. In one of the conversations that I had with Ella the counsellor at Treatment Provider A, she noted that,

'When HIV came out newly, we didn't really know what it was, so people actually campaigned HIV, what I mean by that is that they wanted to create awareness for the public, so they would actually carry a picture of a person before when he was healthy and then when you have HIV, the perception was that you will live until you become sick, becoming skinny, bones, you know, just living like a creature so you will now snap that latter picture. So when they go out for campaign, they will show you her present picture and then the picture before she became sick and they will now show you the picture of when she was really ill, I'm telling you, and now compare the two pictures, so that put a lot of fear, a lot of fear in people and then I think that was what even made the stigma to be more. Once people found out that they have HIV, nobody would even want to speak to you, nobody would even want to sit where you sit, in fact, you can't tell anybody, you know, families were actually even hiding it as much as possible. If they find out that you have HIV, they will hide you in a room, no family wanted to be associated with that, maybe a member of my family has HIV, so once you have HIV, they will actually be locking you in a room without getting any form of medical care, you understand?

Another participant, Ria collaborates this in her own account that at the time she tested positive for HIV,

'people were scared of HIV, really, people were scared of HIV, they will say that person is going to die, quarter to go. They named different names, either

quarter to go, either he is dead person, either ehhe, he is a skeleton with different types of names'

Images of AIDS patients looking weak and emaciated shook public imagination about HIV/AIDS, with many associating skeletal bodies with AIDS and people with HIV were called different names including 'quarter to go'- meaning that it was only a matter of time before death. In the 2000s, as Nigeria's AIDS epidemic peaked, stigma against HIV positive people was so pervasive that those who tested positive kept their status secret, as Ella's account noted. Individuals with HIV may lose family support, may be isolated and forced to look after themselves, as happened within my own family, which I noted at the beginning of this research. Ella notes that publicity campaigns informing people about HIV/AIDS didn't do much to allay people's concerns because these campaigns put fear into people by showing before and after pictures- the before pictures showed healthy bodies but the after pictures showed bodies at the point of death. These images were quite powerful in delivering the message that HIV is deadly and anyone with HIV is at the point of death. As Nigerians share a collective outlook, families preferred to keep any HIV positive relative out of the picture rather than admit to having HIV positive relatives. Those like my relative who experienced stigma felt ashamed and the stigma itself was a heavy burden, which led to a quick downward spiral toward death. Maimuna thought she was going to die when she was diagnosed HIV positive and she feared that she would be stigmatised by others in the community.

Maimuna understands that HIV is a sexually transmitted infection but she insists that she is not promiscuous and she contracted HIV within the context of marriage,

'Na from my husband [it was from my husband].'

Maimuna felt a sense of powerlessness when she received her HIV diagnosis because she thought she would die and she was worried about what would become of her children in the event of her death, as they were still young at the time she was diagnosed. Maimuna sees herself first as a mother and sees her role as their carer,

'Because that time, dem dey say if you get this problem, you go die and I dey fear for my pikin.'

[because that time, they used to tell people that if you have this problem, you are going to die and I was thinking of my children]

This powerlessness was also apparent in Maimuna's response to her mother crying after learning that Maimuna has been diagnosed with HIV,

'She just dey cry. Wetin we go do?'

[she cried. What else can we do?]

Maimuna resigned herself to HIV. She informed her children soon after of her HIV status and informed them that she had started taking medication,

'I just tell them say see the thing wen dey do me, wen they say I dey collect drugs, I say yes.'

[I told them that this is what I have, they asked me if I am taking drugs, I say yes]

Maimuna also informed members of her husband's family of her HIV status and it was then she discovered that her husband's family were already aware of his HIV status and knew that he died of AIDS. Her husband had told his own family members before he passed on and his relatives explained to Maimuna that he did not tell her out of his concern for her. But her husband failed to take steps to protect Maimuna from contracting HIV. Her in-laws were also aware of the possibility that she herself might be infected yet they could not summon the courage to tell her to get herself tested, particularly during the severe illness episodes Maimuna experienced before she was herself diagnosed with HIV.

Apart from HIV, Maimuna has had to overcome tragedies in her life prior to her diagnosis. Her father died when she was very young and she went to live with her paternal uncle who gave her out early in marriage- Maimuna does not know her age but thinks she could have been around 14 at the time, not a particularly unusual phenomenon in Muslim Northern Nigeria. She had eight children, four of whom died in childhood. She experienced poverty during marriage and widowhood and has watched her husband passed away from AIDS. Her last child died the same year as her husband and she suspected that this child might have been HIV positive too, as the child was always sick. At the time of Maimuna's marriage in the 1980s, a key

feature of Northern Nigerian Islamic practice was the seclusion of women upon marriage (Callaway 1987). Seclusion may have isolated women from society but it did not isolate them from the negative economic consequences of dependency on men who are often financially unstable. Maimuna was financially dependent on her husband and when he died, she was left destitute. Northern Nigeria as a whole is the poorest region in Nigeria- compared to other parts of Nigeria, women from this part of Nigeria where the North-Central is also located, are less likely to be educated, suffer higher rate of maternal mortality, have higher rates of poverty and their children are more likely to die from preventable illnesses. As Maimuna did not have the opportunity to go school due to poverty, early marriage and her cultural traditions, she is pushed further down to the very margins of society in being a woman, living in poverty and is illiterate. Financial struggles are never far from Maimuna's life- Maimuna sells snacks so that she could generate extra income for herself but the money she makes is not enough to meet her needs, as Maimuna says that her major worry is the need to make ends meet,

'I dey find money.'

[I am looking for money]

Lack of money was the biggest obstacle to her attending monthly support group meetings, as she does not have the money to pay for transport fares to the treatment unit and she sometimes struggles to get the money for the transport fare to collect her medication from her treatment provider. She was also struggling to find money to pay her rent, bills for amenities such as water and electricity and school fees for her children. Financial worries led to stress, which brought added health issues that left her unable to do much work,

'it's just tiredness, not much, just tired that is what will stop me from doing anything.'

Life with HIV is challenging but she has come to the realisation that there is nothing she can do about her HIV status other than to take her drugs as prescribed to her. Like Rabi, counselling helped Maimuna to address the possibility that because her husband died of AIDS and as they had not been practising safe sex, she too could

be infected. Maimuna remembered that she made the decision that she would live with HIV during the initial HIV counselling process,

'The person wey tell me say wetin I go do if dem find me with this sickness? I tell am say nothing, I go thank God for my life, na so I tell dem. Na hin the come tell me this is the problem. I thank God.'

[The counsellor that diagnosed me asked what I will do if I'm positive. I say nothing, I will thank God for my life, that's what I told them. It was then that they told me that this is the problem. I appreciate God]

Maimuna has internalized messages from her service provider in relation to adherence to her medication and protecting her health,

'make I no smoke, make I no drink nono, Fulani nono. If I wan drink, make I cook am, since that time ma, I no dey take nono.'

[They told me not to smoke, not to drink fermented raw cow milk. If I want to drink fermented raw cow milk, I should cook it. Since then, I have not drunk fermented cow milk].

Maimuna's Muslim faith is important to her living with HIV. She ascribed a spiritual meaning to accepting her diagnosis even in the face of the possibility that she could die. She did not question why she was infected; neither does she apportion any blame to her husband. It seems that the counsellor was afraid that Maimuna would take her diagnosis badly but when Maimuna stated that she would thank God for the diagnosis, the counsellor then told her that she is HIV positive. Ascribing a spiritual meaning to HIV meant that Maimuna could not talk further about HIV since silence offered a deference mechanism against societal assumptions about HIV being the result of sexual promiscuity.

Reflexive thoughts

I spent some time with Maimuna at her house and I carried out all our interviews there. I was not able to do full justice to Maimuna's interview transcripts as much as I would have liked, as her answers were often too short and they lacked the depth of data that I had obtained from other participants in my research. Language barriers played a major part in this, as Maimuna does not speak English- we communicated in pidgin English but Maimuna does not speak it fluently. Maimuna was more eloquent outside of the interviews and also more comfortable speaking her own language- it was only after I returned to London after fieldwork that I realized that I should probably have taken a different approach to my interviews with Maimuna.

This could have included not interviewing her at home, not taping her interviews and perhaps interviewing her in her native Hausa, a language that I do not speak well- I understand Hausa- it was my first language growing up in Nigeria but I have lost fluency and no longer speak it well. But I was also sensitive to Maimuna- she is a poor widow and she experiences fatigue which makes it hard for her to meet outside of her home.

7.3 'From that time, I can open up'- Vickie

Vickie's biggest worry is marriage. She feels frustrated that she is not married or in a relationship that would lead to marriage. This leaves her feeling worthless and this has shattered her self-confidence,

'I'm feeling pain, like how will I remain in pain? Being HIV positive and will I ever ma get married? That's the problem, that's just the situation;

Vickie says that HIV is a problem- it has taken away the possibility of marriage- now that she is HIV positive, she cannot get married. In her interview, she points to the difficult position that she is in when other people talk about HIV in her presence,

'my heart will just beat and if, if I'm kind of in the midst of people and they are talking about HIV issue, then my heart will just beat, it will just beat so I don't want people to be just talking about it.'

Vickie feels anxious about her HIV status, particularly when she hears other people talk about HIV- she finds the public discourse on HIV distressing and it feeds her anxieties about herself and her desired future for marriage,

'I just....let me put this way, I'm worried when I think of myself being positive, I worry and I worry whenever I think, being, I mean, me seeing, who will marry a positive lady, I worry that.'

Vickie feels that society judges women with HIV and because of this, she judges herself, *'I'm worried when I think of myself being positive, I worry'* which represents a gendered experience of HIV. Vickie feels that HIV has given her label because of the moralistic discourse that surrounds HIV in Nigerian society and young, positive

women like her who are of marriageable age are judged harshly by society. Vickie feels worthless and ashamed because of her HIV status.

Living with HIV is not just about the label she has acquired but also about the drugs she has to take,

'I worry about me taking the drugs, when will this stop? That's how I worry.'

The drugs signified to her that she is not healthy and she must take them to survive. It took Vickie many years to come to terms with HIV. Her Christian faith is an important part of her life; it has given her a forum for meeting and interacting with other Christians, thus reducing social isolation; it has also given Vickie hope and encouragement that has sustained and strengthened her. Despite the church's moralistic tone towards HIV/AIDS in the early stages of the epidemic in Nigeria, churches have nevertheless played a major role in facilitating access to care for WLWH- the church was the one place Vickie found emotional relief from HIV and it provided a space for her disclose her status. Vickie's disclosure came in the form of a public testimony in church and it was an emotional moment for her in sharing her status with her church members,

'The church...everybody was...wow...people were very surprised. I cried and cried and cried, it is just for that day.....'

Through disclosure to her church members, Vickie was able to connected to a wider audience,

'Everybody was like...wow... and the people that I don't used to talk to started to talk to me, so then then, I'm free. Because before when I was not open, everything I used to do, I would be feeling guilty and I was like, 'let me not enter this place so that they would be looking at me, that this girl has HIV.' From that time, I can open up, everywhere I go, I will be free because everybody knows.'

Disclosure enabled Vickie to identity with HIV by redefining it from a moral to medical condition that can be treated and controlled with medication. Disclosure also freed Vickie from guilt and shame, enabling her to close the chapter on her old self and embrace a new self that includes living with HIV. The new sense of self is

emphasized by the way Vickie takes care of herself and ensure correct adherence to ART, which is reflected in a healthy looking physical appearance,

'yes, wow, look at me that before I was just thin like this but look at me now, I am fat.'

Despite her worries about her lack of marital prospects and anxieties about her HIV status, Vickie feels that she has reached a point where she could immerse herself in the wider HIV community and could disclose her status to others. In contrasting her previously thin self to her present healthy self, Vickie remembers how she was devastated by her HIV diagnosis, fearing that she had 'died' but over time, she became more resistant to the stigmatising and moralizing discourses around HIV. Vickie is an activist in the wider HIV community and has campaigned for people to test and know their status. She works for an NGO and as part of the condition for employment, Vickie is required to live openly with HIV and to disclose her status. Her job further validates her public disclosure and to some extent, her sense of self as an HIV positive woman.

Vickie cites her mother as her most important source of support,

'My mom still gives me hope. She says to me that's not the end. You can still go on with life.'

Vickie's mother encouraged her not to focus on the negative side of HIV but to continue with her plans for her life,

'I want to achieve what other people are achieving, that is what I want to go and achieve, to add knowledge, to know how to speak better, to know how to read and write, to be exposed to new things like making new friends, different types of people.'

In contrast to Binta, Vickie does not use words such as 'normal' or 'people with our type of situation' to describe her life. Instead, she wants to do what 'other people are achieving', a sense that even with HIV, she can still do what other people are doing. Vickie wants to be financially self-sufficient and she is aware that she needs to further her education so that it could open up further opportunities for her- Vickie

cites the availability of medication for helping her to move on with her life in the context of HIV,

'For me to go back to school, it is better that I learn something that I will hold in my hands, that's what I do. So I won't further my education now but I hope to do so soon because I am seeing that with HIV and medication, I can do anything.'

7.4 'HIV is a blessing to me'- Halimatu

Halimatu is particularly keen to emphasize how she contracted HIV through marriage and in this way, she rejects societal notions that she is HIV positive because she is sexually deviant. Halimatu works as a volunteer within her treatment organisation, where she is seen as an expert who can help others in the clinic. With new patients, she emphasizes her own experience to them,

when they bring this new patient, immediately they come here, you will see they will be looking, emm, tired, they are angry, they will be looking like they are dying, I go and sit with them, discuss with them and I tell them that I am HIV+ for 14 years and I have two kids and they are looking better and they are negative. See I encourage them.'

Halimatu acts as an expert patient to other patients coming to her clinic for treatment and through her role, she has sought to encourage and to inspire them towards integrating HIV into their lives by sharing her own life story with them. Halimatu's account is striking because it emphasizes that one can live long term with HIV and have healthy, HIV-negative children. Previously, HIV positive women were discouraged from having children because of fears that they could pass on the virus to their children but new types of treatment for HIV have made parenthood a reality for many PLWH.

Halimatu participates regularly in support group meetings- these meetings have provided her with coping skills and she particularly values the friendship and support of other HIV positive women in her support group. Attending support group meetings has given Halimatu a platform for public disclosure of her HIV status- her motive for public disclosure is to educate other Muslims about HIV and to help reduce

stigmatisation of people living with HIV- Halimatu says her own experience of stigma has motivated her to speak out about HIV,

'It's not you like it but for you to help another person that is living positive, you just have to say it because when you look at especially this office I am now,

She is also keen to dispel widespread misconceptions about HIV, which has led her to participate in community outreaches. She describes one of the ways in which she disclosed which included an appearance live on television,

'Yeah, sometimes, I open my status out there because there is a time I did a programme in tv and tell them when I got this HIV, how I get on with it, when I was where I am.'

Halimatu found disclosure psychologically beneficial and for her, it brought healing to her biography. Halimatu sees herself as a woman with potential and has re-emphasized her identity as a mother who can provide for her children through her monthly salary. She also sees herself as an important figure to other PLWH in the community,

'It makes me feel free than hiding it... I tell my God I'm doing well. I do everything myself, I work to earn my money, I sponsor my children and myself so I'm doing okay. Sometimes I even used to tell them, 'HIV is a blessing to me' because it makes me feel that I'm a person that people come to me and ask me of many things. People come from different areas and want to see madam [Halimatu] and they ask me many things. So when they finish, they will feel ok, go, you see, so far that, I thank God.'

Halimatu received strong support from her father and the imam at her mosque when she decided to disclose her HIV status; in a reminder that despite advances in the treatment of HIV, the experience of HIV itself remains a gendered one for women- in this study, women who have disclosed their status rarely did so without informing significant others and it is the response of these significant others that shapes the women's subsequent decision towards disclosure or non-disclosure. Halimatu says that she consulted both men before going public with her HIV status,

'Yes, yes, he know [the imam of her mosque]. The first imam where we used to live before knows my status because he is a friend to my father and you

know, I have told you before that I have been on television to say my status and many people have seen me there.'

Halimatu remembers how she thought her life had ended when she was diagnosed with HIV and she prepared for death. At the time, she was still studying and was engaged in petty trading but she dropped out of school and ceased her business after her diagnosis. When she began taking medication and recovered her health, she began to see things in a more positive light,

'I didn't go back to school because I was thinking I'm not going to make it any more. And the business I was doing before, I have to leave because I was thinking that people will not buy things from me because I am HIV +, before realizing that all that is now ok, so you have gone back and continue as before.'

Halimatu highlighted the positive aspects of living with HIV as she has regained her health and gained a new self,

'HIV is a blessing to me because it makes me feel that I'm a person that people come to me and ask me of many things.'

Through participation in support group, Halimatu gained new friends, support and a renewed sense of hope in moving on with her life. Access to medication has improved her health to the point where she could now reassess her life and her goals, one of which she is attempting to achieve by going to back to school.

7.5 'I have zeroed my mind towards this illness'- Binta

Binta reflects on her life living with HIV and says that she has come to terms with it. During one of the interviews, however, she complained of thrush, which she insisted on treating herself because,

'it's just a minor thing that can happen to a normal person, I mean somebody who is not positive, you know where I am coming from.'

Binta is aware that there is treatment for HIV but she has not yet started treatment, as her CD4 count is still very high and she remains healthy. It is the limited means of

Nigeria's public healthcare system that has rendered Binta's complaints of thrush trivial and insignificant and it made her feel too embarrassed to seek treatment for thrush.

The language that Binta uses is quite important in the way that she constructs HIV. Binta only used the word, HIV, twice in all three interviews, preferring instead to call it, *'this sickness.'* Words such as *'normal person'* and *'normal people'* reflects Binta's anxieties about HIV- she wants to be seen as a *'normal'* person doing the same time that *'normal people'* are doing. These words also reflects the fact that Binta does not want to be defined by HIV yet she has internalised the negative social construction of HIV as a disease that is not *'normal'* and she herself is therefore not a *'normal'* person.

HIV has forced Binta into a world of losses- she has lost a past, present and future- she lost her past because of her divorce, she has lost her present because she is HIV positive and she has lost her future because she may never remarry nor have more children. In her eyes, these losses did not happen to *'normal people.'* Being married conferred a degree of normality as it gave her a degree of social protection and cover for HIV but divorce means that she has to confront HIV on her own.

In coming to terms with HIV, she rejects the notion that she contracted HIV because of sexual promiscuity by making the point that she contracted HIV through marriage,

'I give God the glory that mine just came through marriage, not that I was a wayward person.'

Binta does not want to disclose her HIV status publicly because of her fears of stigma but in reality, this was not something that she could control, particularly as she attends a treatment organisation which has a large treatment programme for PLWH and she meets other people who are also coming for treatment. Ironically, Binta and I arranged to meet on a particular day for the second interview at the clinic where she attends for regular check-up and she bumped into an old friend she had attended secondary school with; both women hugged each other with shouts of joy and both admitted their HIV status to each other- like Binta, this friend lost her husband to an AIDS-related illness and she told Binta that she was at the clinic to

collect her medication and they promised to keep in touch by exchanging phone numbers. Binta does not want to disclose her status but in bumping into her friend at the clinic, the clinic therefore became a safe place for Binta to talk about life in the context of HIV. This is why Binta could say,

'Well, actually, as I have told you, I have zeroed my mind towards this illness so I never gave it a terrible thought that it was a sign that it was going to be worse.'

Binta informed her father and an aunt that she has HIV and has put a brave face in assuring them that,

they should not worry... they were sad but not anymore because I'm strong. I was assuring them that I will be fine and I know I will be fine, yes.'

Like all the women in this study, Binta had never imagined a life trajectory where she has to live with an illness that brings stigma, shame and even death, even though there is treatment for HIV,

'But from time to time, I feel sad. I feel sad as a human being, so sad, so sad, so sad.'

Binta understands that HIV is a medical condition but she frames it from both medical and moral discourses. In coming to terms with her new self, Binta told me off the record that she wants to remarry and have more children but preferably with an HIV positive man with whom she could have a sense of being herself and of having some social protection through marriage. The other condition is that the man must be a Muslim like her.

Binta found counselling useful in allaying her fears about HIV,

'I find it very educative, very informative and it consoles my heart.....if not for that, I would have been thinking negatively and that would have done more damage.'

She also cites her faith as a Muslim for her decision to accept and to live with HIV even if it is one that brings her shame and makes her sad,

'As a Muslim, we are asked to accept whatever comes our way, positive or negative, with good faith because trials will come from all ends and I give God the glory that mine just came through marriage, not that I was a wayward person, so it didn't take me that long. But from time to time, I feel sad, I feel so sad as a human being, so sad, so sad, so sad.'

Like Halimatu, Rabi and Maimuna, Binta is keen to stress that it was through no fault of hers that she contracted HIV; rather than being a 'wayward person', she was infected by her husband, so she rejects the label that society has attached to women like her. Binta remained upset by her divorce, viewing it as disruption because it was unexpected and she had been unprepared for the possibility of living with HIV on her own.

She is also attempting to put her life back together, a process that she has already begun by disclosing to her father and one of her aunts and was working on how to disclose to other members of her family who were not yet aware of her status at the time of our last interview. She was preparing to live on with HIV on her own terms- this way, she could control who she would inform of her status, when and how. She would choose her future husband on her own terms because she wants someone she could feel free with rather than hiding her status, which was a stressful burden. She feels she can only achieve normalcy with an HIV positive partner who would help alleviate her sense of difference, provide psychological and emotional support and restore normality to her life. Having a supportive spouse would enable her to integrate HIV into her identity. Because she remains healthy, she is able to move on with life with the knowledge that if her health deteriorates, she could successfully access treatment to control the virus.

7.6 HIV is nothing, HIV is nothing, except if you don't take your drugs-Grace

Despite the multiple losses she has suffered, Grace acknowledges that medication has sustained her life,

'I was thinking that this HIV sickness is just like something that I will die quickly, something that will kill me quickly but I sit and think about things and if you see what is going on now, HIV is nothing, HIV is nothing, except if you

don't take your drugs.'

Grace understands that she can live with HIV if she takes her drugs on a regular basis. In referring to her medication, she highlights how it has made a difference to her life because her child is not HIV positive,

'I born in 2010, so I have pregnancy, so I went to the hospital. They now told me that I will take medicine so that I can be able to save the baby inside my womb.'

Grace regrets that she has access to medication that could have saved her parents the unnecessary pain they went through. ART was not widely available at the time her father died and her mother deliberately refused to take hers when they became available because of the judgemental attitude she experienced at the hands of staff at her treatment provider and in the end, she refused to continue taking her drugs,

'So I always feel that bitter in my heart that I cannot be able to help them when they are feeling that pain but my mother, she really suffered before she died so that was really more painful than my father own. The death of my mother, she was the one that refused to take the medicine, she say she is not going to take it.'

Despite the challenges- the physical symptoms of HIV including fatigue, the side effects of her medication, discrimination on the basis of her HIV status and gender and her financial worries, Grace has been able to construct her identity of living with HIV around her drugs and her memories of her parents' experience with HIV. The ARVs she takes are her lifeline because she wants to continue living. Grace insists that her death would not be as a result of HIV but from another illness,

'I always pray to God that it is not the HIV that is going to kill me but rather a different sickness but not HIV.'

Grace's faith has been important in helping her construct life with HIV- it gives her a sense of meaning and purpose and it gives her the strength to take her medication. She is determined to stay alive and she will continue to taking her drugs as prescribed by doctors- this is why *'HIV is nothing, except if you don't take your drugs.'*

7.7 'After all, it's not being written on my face'- Irene

In the early 2000s, large billboards appeared in major cities in Nigeria to inform people about HIV/AIDS, with the slogan, 'AIDS no dey show for face', [AIDS doesn't show on your face]. This campaign was designed to warn people that HIV/AIDS is real and to encourage people to test to know their status and to warn people that it is not possible to tell one's status simply by looking at one's outward appearance. Irene took note of this message. Now that she is positive, Irene understands that she has to move on with her life. In coming to terms with HIV when she began receiving treatment, she felt that she had to move on with her life because,

'I should just move on with life, after all, it's not being written on my face.. I think it made me to take courage that I can do things... I can face challenges and I always try to get things on my own, not relying or waiting for somebody to give me something, that is one thing I have got to discover with this, that's the positive side of it that I have discovered. I know that I want to achieve things, I want to make something great in my life.'

By this, she meant that HIV has not manifested physically on her appearance and she has not disclosed her status. Therefore, she would not be the subject of gossip and her reputation and society would not question her moral character. In coming to terms with HIV, she acknowledges that by managing her life with medication which minimizes the symptoms of HIV even though taking drugs is not easy, she could hold a job and can sustain herself without depending on someone else to provide. She wanted neither pity nor charity but the chance to prove that she is a woman who can make valuable contribution to her society. In coming to terms with HIV, she defends herself against the anxiety she has about her 'spoiled name', particularly in insisting that,

'There are sicknesses that are more than HIV. Because I have been having so many counselling and I have hope with my faith- I am a Christian. My Bible tells me that there is no sickness that my God cannot cure.'

She also points to her strong spiritual relationship with God, which is important for her psychological wellbeing and the counselling sessions that she had have enabled

her to come to terms with HIV. Irene is also keen for a cure and she still believes that her faith in God would heal her,

'And I believe that one day, it will be all history because I am holding to it. Me being positive, how will I start living my life, how will other people see me? But because of the courage that I had in my faith and in my God that I feel that I'm not HIV positive.'

Irene was encouraged by her pastor to continue believing and praying to God for a cure; in this, she is similar to Pamela who stated in chapter 6.4 in this study, *'it might sound funny but it's because I strongly believe that in a matter of time, I will be negative. I don't know but I have that assurance.'* Irene describes how this process played out with her pastor,

'One days, I am going to be diagnosed and it is going to be negative because I had a discussion and prayer session with one of my pastors last weekend and he say I should go for a test and even no matter what result I will get, I shouldn't be discouraged. I should move on, that one day, it will be a history and I take that courage. As of Monday, I went for another test again, just on my own, I went for a test. Actually, I didn't tell them I had HIV, just that I had a test last year, that I just want to confirm myself again with the high spirit in me that the result might be negative but then the outcome was still + but then I didn't, I wasn't angry with myself nor with God. I say, I know, one day there is going to be a cure. I collected the result, in fact, I still have it with me and I still believe that one day, it's going to be okay. I'm living my normal life, because I don't want to people around me to be feeling bad, ok, just stay away from me.'

Charismatic Christian faith healing is a powerful presence in the lives of many Nigerians Christians living with HIV. Membership in Pentecostal churches in Nigeria exploded during the economic crisis of the early 1990s, when people began to seek spiritual relief from these hardships- this was also something I witnessed within my own family too, with several of my relatives declaring that they had become 'born-again' Christians. Pentecostal churches offered an alternative to mainstream Christian churches and new generation pastors could draw on messages of healing, miracles and prosperity to attract new members. This period also coincided an emerging HIV/AIDS epidemic in Nigeria and in the absence of an effective public health system, many Nigerians turned to religious organisations for relief. These organisations were critical in meeting the health needs of Nigerians, particularly in

rural areas like my hometown. Some Nigerians also sought help from alternative, traditional healers.

During my fieldwork, I heard stories about some charismatic and Pentecostal churches promising cures for HIV and other infections and some pastors have encouraged their members to stop taking their medication. Advertisements often appear in national dailies, promising cures for HIV and other common infections and women are particularly vulnerable to false claims of healing, as I saw several times during fieldwork in Nigeria. I understood the appeal of the faith healing messages in the context of the economic marginalization of women and the emotional devastation of HIV/AIDS. Gender-based power is a key feature of this appeal too, with powerful men wielding enormous power over women who are more likely to attend churches than men are. Irene went to church to take part in a faith healing session where the pastor told her that she has received healing; after this, she went for another HIV test believing that her result might be negative but it was still positive. Once she received her result and it was still positive, Irene had to resign herself to her HIV status. Irene's faith in God provide an important support system for her in coping with HIV, particularly given her hopes of a cure. Her strong religious belief persuades her to take her medication.

Summary of theme three: disrupted lives, 'repaired' biographies

Aside from the availability of ART, religion and spirituality have become key factors in helping the women in this study come to terms with living with HIV and religious institutions hold an important place in the lives of the women in this study. In coming to terms with HIV, some of the participants have mobilized resources such as engaging actively with their HIV status through voluntary work, community outreach programmes to inform others about HIV/AIDS, religious activities, counselling and disclosure. The women told stories of the shattering blow they experienced as a result of their HIV diagnosis and of their struggles to live with HIV and to make sense of it. Most participants turned to their religion to find emotional and psychological support in coming to terms with HIV. What emerges from my research is that despite treatment, HIV remains a much-misunderstood illness and HIV positive women remain at risk of being stigmatised and discredited.

The participants' interview transcripts describes the trauma of living with HIV, which caused great distress to the women. Although life will never be the same because of HIV, the women have found ways of coming to terms with it. HIV challenged their self-concepts and many have internalized prevailing negative notions of HIV yet these women themselves have identified their own inner strengths, particularly through public acts of disclosure and their faith in a Higher Being.

7.8 Reflections on fieldwork and data analysis

I spent approximately twelve months on intensive fieldwork research in Jos for much of the year 2013 with visits again in 2014, 2015 and 2016 to see the participants and catch up with events in Nigeria. I built and maintained relationships with most of the participants though I generally left it to them to guide the relationship in order to ensure that they were never under any pressure to participate in my research. Through these interactions, I came to understand more about HIV and observed how the women make sense of living with HIV as well as the broader social framework around HIV/AIDS in Nigeria. Christian and Muslim women participated in my research but I found it harder to reach out to Muslim women. Nevertheless, I was able to recruit five Muslim women to participate in my research. The broader socio-religious tensions that exists between Muslims and Christians in Jos also had an impact on my relationship with Muslim women as life in Jos became polarised between the two communities due to religious clashes when I was in Jos and as a result, religious and social considerations shapes encounters between Christians and Muslims. Despite these constraints, I was able to interview a Muslim woman who requested that I interview her in her own home, as the clinic was too far and she did not have money for the transport fare. Another Muslim woman mentioned that she would prefer to come to the clinic for her interview, as my coming to her house would attract attention from her neighbours.

As I look back to the time that I spent carrying out my research in Nigeria, I became conscious of the need for a critical reflection of my time in Nigeria. I reflected upon the small scale of the study. Could the findings be considered to represent Nigerian women? My argument has never been to lay claim to the 'truth' but my study provide the basis for broader enquiry with a larger group as well as providing a useful foundation for further research by other researchers who are interested in understanding the experiences of HIV positive Nigerian women. Can I claim to know everything about these women and their experiences? I was aware of the unequal power relations between the participants and myself and the communication difficulties that I had with one or two of the participants made me aware of the socio-cultural differences that exists between the participants and I. By engaging in the process of reflexivity, I became aware of how my research changed some of the previously held assumptions that I had prior to my research. I began my research with westernized views on what it means to be a young woman in the 21st century- a

woman with the chance to strive to be what she wants in life including career goals, educational aspirations and challenging notions of gender inequality but my encounters with the participants in my research study changed my perceptions. I began to appreciate the opportunities that I have had in life relative to the participants and I have learnt to appreciate and respect the women themselves for overcoming difficult life challenges.

During my time in Nigeria, some participants and treatment providers saw me as an 'expert' and as someone who was close to the national corridors of power even when I explained to them that I was a student carrying out doctoral studies on women living with HIV. Although it is true that at the time I first started fieldwork, I knew some government officials, I was not in any position to influence federal policies nor direct where funds were distributed. The effects of economic hardships are widespread and difficult to escape from and Nigeria is a hierarchical society where women are expected to know their place and women are held to higher moral standards than men are. Women who fail to follow social expectations can acquire labels and as such, many find it difficult to break social modes. The women who took part in my research are mostly women who are struggling financially and have not had access to the opportunities that I have had. Did these differences have an impact on the women's responses? Did these differences have an impact on my interpretation of the data from the interview transcripts? The experience of interviewing Muslim women underlined cultural differences between these women and I, with most insisting on meeting in the clinic for their interview sessions. Christian women generally selected a variety of locations for meeting up for the interview sessions, including their homes, parks or clinics.

Language was initially an area that I had some difficulties at first. The selection criteria called for participants who are fluent in English but the counsellors found it difficult to approach clients who are fluent English speakers but in the end, this did not matter. As I became more engaged in the research environment, I gradually overcame this challenge. I learnt some Hausa and picked up Nigerian pidgin English. In this way, I was able to ensure that language did not constrain the phenomenological demands for myself and the women in a study that seeks to explore the world through the participants' own accounts. In addition to interviews, I also kept field-notes, which helped in analysing my data. During interviews, I generally gave the participants space to speak as freely as possible about their daily lives in the context of HIV and could induce both from the said and unsaid. My own knowledge of Nigerian society and HIV was quite helpful in enabling me to make sense of the participants' experiences and to interpret as they see and understand them.

Returning to London to start working on transcribing interview transcripts was a long, difficult and time-consuming process. I began transcribing the interviews from February 2014, a process that took nearly six months as I went through each interviews individually. Firstly, I listened to each interview individually, manually transcribed them, read my field notes and then listened again before beginning the process of interpreting the emerging data. Disengaging myself from fieldwork was a gradual process but I have come to realise that in a sense, I will never be completely

free from the world of some of these women just as they will never completely break free from mine. I paid visits to participants to thank them for their cooperation when I returned to Nigeria to see some of the participants again in 2014 and 2015- these were mainly the participants who agreed to keep in touch with me.

Chapter Eight: Reflections, discussion of findings and conclusion

Introduction

In this chapter, I reflect on my research which explored several aspects of participants' experiences of living with HIV, in keeping with a feminist approach. This approach also explored contextual factors, including layers of exclusion and oppressions which shaped the women's experience of HIV. In reviewing the findings that emerged from the present study, I have noted the treatment providers' standpoint and the disconnect between their approach and the realities of women's lives. The participants experience several layers of exclusion and oppressions which have shaped their lives and they were themselves able to describe in some great details the factors/issues which shapes their experience of HIV. The chapter then presents a synthesis of the thesis, provides suggestions for future areas of research and concludes with recommendations for treatment organisations.

8.1 The present study

My research explored the experiences of eleven HIV positive Nigerian women in Jos, North-Central Nigeria. In carrying out this study, I have focused on a developing country in the global South and have incorporated a feminist approach to the research methodology alongside Bury (1982)'s notion of chronic illness as biographical disruption. I have attempted to situate these women's experiences within broader social, cultural and economic contexts in Nigeria. Through my research, I have demonstrated the need to recognise the wide range of experiences of Nigerian women living with HIV as well as the commonalities that link them together as women living in society where women are subject to dominant patriarchal tendencies that puts them at a distinct disadvantage vis a vis men. My research has highlighted the importance of capturing Nigerian women's experience of HIV through their own voices and the importance of recognising the complex ways in which HIV impacts on these women's lives.

8.2 Treatment providers' standing point: Living Positively

As a starting point for the discussion, I note that the treatment providers in this study relied largely on international donors, mainly from the global North, to provide funds and drugs. These funds pay for staff salaries, maintain the clinic and fund prevention programmes and as part of their commitment to donors, treatment providers have stressed on the need for complete adherence to patients accessing treatment. Patients must take their drugs every day at the same time for the rest of their lives and they are encouraged to live positively with HIV, including safe sex, ensuring access to clean water, having a balanced and nutritious diet and taking preventing measures such as protecting themselves against malaria. However, as one participant, Vickie, has noted, HIV *is a raw experience*- this is the most powerful statement from a participant who has made it clear that HIV is a painful and undesirable condition that has social, economic and cultural implications for women. The 'Living Positively' message that treatment providers use to encourage women to live with HIV has silenced women but I also found that this message reinforced the skewed gender relations that women already experience within Nigerian society.

In drawing out the experiences of participants in this study, it becomes clear that for these women, there is nothing remotely 'positive' about living with HIV. There is medication that has prolonged lives and minimized the symptoms of HIV but it is difficult for them to live with a condition that is highly stigmatized; instead, participants see HIV as a condition that has to be managed with in the context of their fractured lives. The women's accounts of their lives demonstrates that there is disconnect between the 'Living Positively' message and the participants' own experiences of reality with HIV. HIV is *a raw experience* that exposes women to shame, ridicule, stigma and discrimination that they might not otherwise experience if they are not HIV positive. It forces women to review their relationships with their social world in the light of their HIV status. HIV disrupted social relationships as well as how the women viewed themselves, which itself is arguably a form of biographical disruption.

8.3 Discussion of the findings

I used Bury (1982)'s notion of chronic illness as biographical disruption as well as applying feminist lens to explore the themes that emerged from the participants' interview data. I focused on the gendered experiences of HIV and drew out contextual factors that had an impact on these experiences. By adding a feminist lens to reflexivity and IPA, I was able to focus on the gendered experiences of HIV- the women themselves articulated their own experiences, with regard to living with and coming to terms with HIV, the strategies they devised to cope with HIV and their relationships with their wider social world. They described their fears of stigma, discrimination and for unmarried women in particular, their fears that they may never get married. In the next sections of this chapter, I discuss more broadly the conclusions that arises from my research.

8.3.1 Testing Positive

This overarching theme explored the participants' experience of testing positive for HIV. Testing positive resulted in uncertainty for the women; there are very few studies on Nigerian women's experience of testing positive for HIV- the current study was able to provide a valuable insight into the reactions of a group of Nigerian women to an HIV diagnosis that was for the most part unexpected. It is clear from the participants' accounts that living with HIV is stressful and disempowering. HIV exposes them to shame, ridicule and stigma and discrimination. Their gender intersect with HIV to shape their experiences of living and of discrimination on the basis of their HIV status and gender. Some participants recalled how treatment providers and society depowered them when they were diagnosed with HIV.

Whilst undertaking an assessment of the clinical environment where the participants are receiving treatment, I was struck by the situated reality that participants had to face living with HIV. The 'Living Positively' message promoted by the treatment centres where I carried out my research has been designed to encourage correct adherence to ART medication, healthy eating (fresh fruits and vegetables), keeping active and improved psychological wellbeing (through engagement in support groups, disclosure and social/political activism). In reality, however, as the

experiences of the women in my study illustrates, living with HIV is not an easy process- this finding that has been replicated in other studies which have noted that HIV positive women have to deal with psychological trauma, poverty and health challenges (Walstrom et al 2013; Aulette-Root et al 2014). HIV is a very much a gendered experience for the women in who participated in my research.

As one participant mentioned in her interview, 'I wept, I wept, I wept, I couldn't walk from that office', being told that they are positive is not something that participants had expected and some had not even been aware that they had been tested for HIV. In reflecting back on the interview transcripts of several participants, I was struck by a commonality that emerged across the interview transcripts: HIV is a severely disruptive event for the participants as it was neither an expected nor particularly welcomed event to life as they participants knew it- this fits into Bury (1982)'s first description of biographical disruption- the taken for granted aspects of life. The initial onset of chronic illness limited some of the participants' ability to function, resulting in the disruption of everyday life structures. For these women, the disruption to their lives was exacerbated by socio-economic and socio-cultural factors relating to poverty, unemployment, low status of women in society and discriminatory attitudes towards women living with HIV/AIDS. I observed that in some cases, HIV also appeared to disrupt their explanatory systems as highlighted by (Bury 1982).

They associated HIV with a stigmatized identity that devalued them- they felt guilty, ashamed and a sense of dirtiness (sex); HIV devalued them as wives and mothers and for unmarried women in particular, as potential lovers and marriage partners. The participants also see HIV as a burden that is somewhat at odds with their valued social identities as good wives and mothers or potential wives and mothers and HIV is not supposed to happen to women like them because, to use Halimatu's word, '*we don't go out, we don't do all sort of things, where would I get HIV?*'. As the review of the literature in chapter two of this thesis notes (2.4.1), stigma is an attribute that is deeply discrediting, resulting in the loss of status and discrimination against the women on the basis of their HIV status. Indeed, some of the women in my research felt that they had lost their status as a result of HIV- some were widowed by the deaths of spouses from AIDS, some were divorced by their spouses while unmarried women have been seen as undesirable marriage partners- one of these women had

already been rejected by a potential partner because of her HIV status (Vickie) and another participant was in a relationship where her partner toyed with her emotions because of her HIV status (Pamela), which left her feeling ambivalent.

I also observed how the women internalized the negative and stigmatising societal views of HIV which resulted in a further disruption of their biographical trajectories. Fear of discrimination and stigma meant that some of the women continued to keep their status secret even from their families- this was particularly the case for Muslim and unmarried women who seem less likely to disclose their status and are in general less likely to access support facilities in living with HIV. The Muslim women in my research veiled themselves as mandated by Islamic custom but to me, the veil is also symbolic because it accorded them protection from the wider society by enabling them to disguise themselves and therefore, their status from others. Under their veil, these women could potentially hide markers of HIV from the wider society. Those participants who have not disclosed their status have cited stigma, discrimination and fear as reasons for not disclosing- these reasons are entirely valid and reflect the disruptive elements of HIV. I saw how for some participants such as Cher, Irene and Pamela, HIV seemed to define their relationships with the wider society. It profoundly affected their attitudes, mental health and their sense of self.

In his study, Bury (1982) highlighted the multiple ways in which chronic illness leads to a fundamental rethinking of one's biography and self-identity. Bury (1982) further suggests that chronic illness disrupts the structures of everyday living not only for the individual but also their family and support systems. Bury (1982) also highlights how biographical disruption occurs on multiple levels by providing specific examples from his own study of clients who had been diagnosed with rheumatoid arthritis. The participants in Bury's (1982) study made references to the ways in which rheumatoid arthritis brought an awareness of oneself and existential issues which forced them into a world of 'pain and suffering, possibly even death, which are normally seen only as distant possibilities or the plight of others' (Bury 1982:169).

I also observed similar experiences among participants in my own research where being diagnosed with HIV is a significant event that marked a disjuncture for the participants because it threatened the continuity between their old and present selves (the self at the time of their diagnosis). Their memories of being told that they

have tested positive for HIV were still vivid in the minds of most participants even after so many years of living with HIV- this suggests to me that the participants see HIV as a significant event that marked a breakdown in their relationship with their social world. Being HIV positive has left them devalued and powerless and some of these women described both the lingering physical and psychological impacts of HIV. This in turn led them to perceive HIV illness to be a threat that disrupted their life trajectories not just on the biomedical level but also socially and psychologically.

The women in my research used multiple imageries to illustrate how helpless, worthless and dehumanized they felt on testing positive for HIV. The four women who were diagnosed with HIV in the early 2000s initially associated an HIV diagnosis with death at a time when the availability of ART was limited and simply too expensive for the majority of Nigerians who tested positive to HIV at the time. They viewed HIV negatively, with some participants using metaphors such as 'spoiled name', 'raw', 'death' to describe the impact of HIV on their sense of self. In particular, given the widespread ignorance and judgemental social discourse around HIV at the time, it is little wonder that married participants had great difficulty understanding how they could end up testing positive for a disease that they thought happened only to people who were sexually promiscuous, homosexual or prostitutes. Married participants see marriage as offering a social status and perhaps, a measure of protection from HIV but they also emphasised how they had contracted HIV from their spouses. This shattered their illusions about their marriages and their spouses' fidelities.

As the data presented in chapters four, five and six of this thesis illustrates, when these women were diagnosed with HIV, their sense of order was disrupted and life lost its meaning for them, at least temporarily. They felt that their life had come to an end and feared that there was no sense of continuity. With treatment and counselling, some participants began the slow and gradual process of rebuilding their shattered lives through self-negotiation and constant reworking of their understanding of their self. The women understood HIV to be an incurable but treatable illness. They also attempted to establish a sense of a self with a future, albeit one that includes living with HIV, an illness that still remains socially undesirable. This is what Tsarenko and Polonsky (2011) have termed, 'undesirable

possession' which cannot be willed away due to the nature of HIV as an incurable illness. Prior to their diagnosis, the participants in my study who were unmarried told me that they had imagined life with marriage and children and all participants, both married and unmarried, had expected that life would follow the continuous and predictable path that they knew and understood. But being diagnosed with HIV was a disruption to this predictable life that had already been exacerbated for some women by poverty, financial hardship and previous experiences of loss. HIV brought an added element of uncertainty.

Although improved treatment techniques means that HIV can now be considered to be a treatable chronic illness and nearly all participants are receiving medication, participants pointed out that they were still dealing with psychological issues and side effects from their ART which were at times disruptive. These issues seem to suggest that there is a need for counsellors and treatment centres to be cautious about normalizing HIV. The reality for some participants in my research is that in an environment where poverty and moral judgement against HIV are widespread, HIV can never be considered to be a 'normal' illness, similar to observations by other research studies (Walker 2020; Walker 2019; Mazanderani and Papparini 2015). With reference to my own research, I contend that although HIV can be treated, it is not a 'normal' illness for the participants in my research because of the psycho-social challenges that WLWH have to face.

Moreover, as I observed from the reactions of people who test positive for HIV during counselling sessions, receiving an HIV diagnosis still remains a distressing ordeal for clients. For women in particular, an HIV diagnosis continues to have a negative impact for them because it affects their employment prospects, marriageability for women and child bearing; married women particularly run the risk of being labelled as sexually promiscuous by their family and wider community. Furthermore, HIV has emerged as a disease of difference even in the treatment organisations that I carried out my fieldwork- I observed the physical separation of HIV treatment units from the rest of the hospital facilities in these organisations. This physical separation seems to add to the experience of disruption not only for the participants themselves but also in general for other people who test positive. At two of the treatment organisations in this research, the separation of the HIV treatment unit from the rest

of the hospital also seems to mark HIV as a disease of social and symbolic separation. It is a social separation in the sense that it marks individuals who have tested positive and are receiving treatment from other people who come to the hospital for other ailments and symbolic in the sense that PLWH have to adopt objects that have symbolic meanings such as 'Living Positively', practicing safer sex and attending support group meetings. Some of these symbols were also publicized and came in the form of disclosure of status, participating in community outreaches or media campaign to raise awareness and educate people about HIV.

As Bury (1982) notes, chronic illness affects not only the body but also one's identity, their sense of self and their future. In my reflection on Bury (1982)'s notion of chronic illness with reference to the participants in this study, testing positive for HIV disrupted the women's taken for granted assumptions about themselves and their lives. HIV disrupted the participants' life and forced a rethink on their sense of self.

8.3.2 Living with HIV

Whilst it is true that poverty is widespread in Nigeria, it is particularly amplified for HIV positive women, as the experiences of the women in my own research demonstrates. My research enabled me to reflect on Bury (1982)'s notion of chronic illness as biographical disruption in a low income country; by viewing the participants' experience of HIV as biographical disruption and applying a feminist lens and considering contextual factors, I was able to recognise the multiple ways the participants in my study expressed their views of life with HIV.

In his study, Bury (1982) states that chronic illness has a disruptive impact on familial and social relationships as well as on life for the individual on a more practical level. But in my own study, I observed that in the midst of chaos and disruption, the women in my research attempted to reorder their world after experiencing and recovering from the internal chaos that resulted from receiving an HIV diagnosis. For many participants, the process of healing one's mental and emotional pain began with confronting their inner chaos and making concerted efforts to reintegrate their past and present and hence gain a sense of embodiment through which they began to

recover their sense of self. The women themselves had to rely on their own emotional strength and to devise their own coping strategies.

Once the women began to take ART to treat their physical symptoms and to live longer with HIV, they could reflect on life with HIV. The participants noted that medication prolonged their lives but they still had to deal with uncertainties in their lives. Most participants struggled to make ends meet; the participants in my research could not necessarily be described as poor but the struggles to make end meets bought added stress to their lives. I saw how financial struggles led to some participants experiencing depression and worries about paying for necessities such as the nutritious foods recommended by treatment providers, transport to treatment centres, school fees for their children and rent payments. Additionally, medication sustained lives but it did not reduce their physical or psychological worries and for some, it even added to their difficulties. Participants describe how their medication was a constant reminder of their HIV status. In my reflections on the impact and meaning of HIV for this group of Nigerian women, I note how some participants struggled to explain what HIV means for them as well as their struggles to accept their HIV status.

The word, 'struggle', to my knowledge, is not one that has been defined in psychological and counselling glossary but has been defined by the Cambridge Dictionary as, 'to experience difficulty and make a very great effort in order to do something.' The Cambridge Dictionary also proposes that 'struggle' means, 'a very difficult task that you can only do with a great effort' and a 'physical or mutual fight.' With reference to my research, the term 'struggle' refers to the efforts that these women have made in dealing with the challenges of HIV. Life was already challenging for these women in the face of pre-existing circumstances including the need to make ends meet, illiteracy and socio-cultural and economic marginalisation on the basis of their gender and social status. HIV brought added struggles including the need to stay alive by ensuring access to nutritious foods, correct adherence to ART medication and adequate access clean water while having to perform multiple roles such as being mothers and carers. Many of the women struggled to secure gainful employment to support themselves and their families and some were even the sole breadwinners.

Although HIV may no longer be considered life-threatening, for this group of women, it remains life-altering and life-shaping as it leaves women having to renegotiate their biographies and sense of self. At the same time too, there was a sense of helplessness among some of the participants. In a resource-challenged environment like Nigeria, women also have to live with uncertainties that comes as a result of HIV, particularly in the light of international donor fatigue which may affect access to treatment in future. They have no control over the nature and severity of their illness as well as future pattern of accessibility to lifesaving medications and will increasingly have to confront the possibility of death if access to treatment is threatened by factors outside the women's control. Even when I was in Nigeria in fieldwork, I could see the evidence that treatment providers were already having issues with procuring drugs- one woman who was previously a patient at Treatment provider B relocated to Lagos and started receiving treatment there but she had to revert back to receiving treatment in Jos, as treatment centres in Lagos ran out of the drug she needed. It is women who will be left most at risk if their access to treatment is threatened.

For women who are traditionally vested with defined social roles such as wives, mothers and carers, the experience of chronic illness affected these participants' sense of self. An HIV diagnosis came as a shattering blow to the participants. With HIV illness, how could they look after their children and husbands? For unmarried women, could they get married? Or have children? How do they explain HIV to their society? In raising these questions, I am reminded of Squire (2003)'s argument that women's experiences of HIV are rather distinct from those of men, even allowing for epidemiological and cultural similarities, with women are more likely to be systematically marginalised and discriminated against on the basis of their seropositive status. Apart from their financial hardships and psychological issues such as stigma and lack of self-worth, off the tape recorder some of the women expressed anger, betrayal and a sense of bitterness towards their spouses/partners who had infected them and some felt ashamed that other people's behaviour towards them were or would be influenced by the fact that they are HIV positive.

In reflecting on the data from the participants' interviews presented in chapters four, five and six of this thesis, I note that participants had varying experiences of

biographical disruption. For some women, there was a biographical disruption in the maintenance of balance between their former, present and future self. By this, I refer to how participants struggled to reconcile themselves to HIV. I am reminded by the observation made by Baumgartner and David (2009) that being on medication often marks a turning point for individuals living with HIV as HIV can be lived with, provided that one adheres correctly to their medication. Nonetheless, it did not stop participants from mourning the loss of their old self, though not all of this was necessarily due to HIV. Some of the women spoke of a loss of a future self- this was particularly true of the unmarried women because prior to HIV, their future included plans for marriage and children but HIV seems to have act as a barrier to this future. In this sense, being positive forced the women into what Bury (1982:169) refers to as a 'fundamental re-thinking of the person's biography and self-concept.' Participants were acutely conscious of how HIV altered society's perceptions of them as women.

In living with HIV, I also note how thoughts of death were never far from the minds of these women- many thought of death when they received their HIV diagnosis- in a sense, they experienced death in the sense of losing their old self and the birth of a new self. Some such as Ria spoke of death in more explicit terms to describe the impact of HIV on their lives while other participants saw death as terminating their life for good. As Gosselin et al (2017) have noted, HIV continues to be seen as a biographical disruption which can have a negative impact on all aspects of an individual's life, including their personal and professional lives, their sexuality, social life and general life expectations. For some of the participants in my research, biographical disruption was not just one event but something was repeated over and over again as some of the women continue to deal with losses on multiple fronts in their daily lives.

As part of the process of reworking their biographies, the women in my research have had to develop an explanatory framework to give meanings to their experiences of being positive. Being diagnosed positive was a deeply disrupting and distressing experience for the participants. In explaining their status, some of the participants saw it as extremely disruptive and hard to live with; it was a 'raw' experience that profoundly affected their identity because HIV had an impact on their social roles as mothers, wives and as humans. The women who were able to re-

establish biographical continuity made references to the significant role that their spiritual beliefs have played in shaping the gradual integration of HIV into their lives and identity- the reference to biographical continuity here is made in the sense that HIV was no longer these participants' most salient identity but one of a number of identities the these women had.

Many of the women who participated in my research have been forced to rework their biographies and to rethink their sense of self upon being diagnosed with HIV. Pre-ART literature suggested that for people who were diagnosed with HIV in an era of limited treatment, being HIV positive was their most salient treatment but the introduction of an effective treatment regime transformed the lives of PLWH. The participants in my study who were diagnosed with HIV before 2005 at first saw being HIV positive as their most salient identity due to limited availability of ART treatment at the time they were diagnosed and many thought that they would die early. In my discussions with counsellors, particularly those at Treatment Provider C, it appears that early counselling techniques focused on preparing clients for eventual death, with one treatment provider encouraging women to prepare memory boxes for their children in the event of death. It is perhaps not a coincidence that most participants attending support group participants in my research are the women who were diagnosed prior to the introduction of PEPFAR in 2004. These women are also active HIV ambassadors and educators as well as church leaders and medication gave them a renewed sense of self in living with HIV. It seems likely that previous counselling about death may have given the women who were diagnosed prior to 2005 a new lease of life for which they are determined to make the most of their remaining lifespan. From 2005 onwards, there was an expansion in treatment programmes from donor organisations to PLWH and most participants in this study are now currently receiving ART medication free of charge from treatment providers. In recent years however, a shortfall in funds means that in an effort to cover the gap in funding, treatment providers have started charging for some services such as CD4 counts and treatment registration fees.

8.3.3 Disrupted Lives, 'Repaired' biographies

In my reflections on Nigerian women's experience of biographical disruption, I give due consideration to the final overarching theme identified in my own research and took account of the steps the participants took in coming to terms with HIV, or in the words of Bury (1982:170), 'the mobilisation of resources in facing an altered situation.' The women's interviews revealed a desire to regain a sense of self. In discussing life with HIV, the participants experienced a sense of mourning. They mourned the loss of their former identity. Specific examples of these losses were presented in chapter chapters four and five of this thesis where participants spoke of losing out on education, marriage and or companionship and motherhood which are significant means of identity for women in Nigerian society. This sense of loss was particularly acute for unmarried women since marriage and motherhood are considered to be the primary identity for African women (Chisale 2018).

Despite the disruptive effects of HIV, several women in my research were nevertheless determined to move on with their lives. Some had reconstructed and renegotiated their lives and had gained a more coherent sense of self and therefore a newly negotiated identity that went with the new self. In chapter six of this thesis, participants spoke at length of coming to terms with HIV and their experiences suggest that women living with HIV have to deal with issues relating to psychological wellbeing, disclosure as well as negotiating access to safer sex. This finding has been replicated in other studies which have shown that HIV is a long-term condition that affects not only one's physical health but also had significant psychological and social implications including stigma and discrimination on the basis of one's HIV status (Kontomanolis et al 2017; Beres et al 2017). These studies have generally also noted that HIV is a chronic condition that can never be normalized, a view that lends support to Bury (1982)'s notion of chronic illness as biographical disruption. In another study, Squire (2013) argues that HIV is not like any other chronic illness, pointing out that Africans generally associate HIV with sexual immorality and death and as result, people with HIV experience discrimination and stigma.

In chapter two of this thesis, I note that Goffman (1963) refers to stigma as a depowering and discrediting label that can change how people view themselves. In

my research, some participants spoke of how fear of stigma prevented them from disclosing their status which they already felt ashamed of. They associated stigma with rejection and believed that they would be seen as HIV positive women rather than as women who can contribute positively to their society. It also seems clear from my observation of the participants' world that they valued social acceptability by others and in fact, some went out of their way to achieve social acceptance, for example, Irene getting married after she was diagnosed with HIV.

The women's relationship with themselves and wider society was fundamentally altered by HIV. Adapting to life with HIV is not an easy process- in making this assertion, I call for the need to consider the nature of HIV as experienced by the women themselves. HIV is a lifelong illness and the women have to take medications for the rest of their lives to manage their illness; these medications must be taken on a daily basis at the same time, a process which requires much discipline which can be difficult if there are side effects (Bukonya et al 2019; Liamputtong et al 2014). At the same time, the women are also advised to adopt specific measures such as safe sex, access to clean water and take preventive measures against malaria. The idea espoused by treatment providers is that with ART, it is possible for women living with HIV to attain normality; in fact, the notion that treatment can restore a sense of 'normalisation' to one's life in living with HIV seems to have received some attention in the literature. However, as I previously noted elsewhere in this chapter, normalizing HIV does not take into account the psychological impact of HIV.

The reality that I observed from the participants is that WLWH still have to negotiate the challenge of disclosure, correct adherence to medications and negotiate safe sex practices with condom use, all of which further emphasises to the patients themselves as well as the people around them the reality of being HIV positive. As Arrey et al (2015) note, even with treatment, HIV is still not considered a 'normal' illness, which makes it hard for WLWH to live with it. The experiences of the women in my study shows that even with effective medication however, uncertainty remains a key feature of life for people living with HIV/AIDS. The women here understood that they remained susceptible to a range of illnesses that they have no control over. Neither are they able to predict the nature, course and duration of symptoms or illnesses which varies from one individual to another. In Bury (1982)'s theory of

biographical disruption, uncertainty seems to reinforce disruption. In spite of challenging circumstances, many of the participants have attempted to establish a positive identity. As can be seen from the findings of my study presented in chapters four, five and six and discussed in chapter seven, most participants have adapted to some varying degrees to living with HIV. This may be because they feel that they have no choice than to do so and for some, in fact, there were no other alternatives than to move on with their lives. If they refuse to do so, who will look after their children in the event of death? Or them in the event of life threatening illnesses?

In my reflections on the participants' experience of biographical disruption, I gave also due consideration to the third aspect of Bury (1982)'s theory, namely the mobilisation of resources to deal with an altered situation. One important observation that I made from my fieldwork was how spirituality appears to play an important role in shaping the participants' lives and attitudes towards living with HIV. I was not able to determine whether participants became more spiritual or religious because of or in spite of HIV but I noted that spiritual belief enabled some participants to let go of past emotional hurt and trauma.

Regardless of whether they are Muslim or Christians, most women believe that God (Allah in the case of Muslims) is the ultimate creator and decision maker and HIV represent a test of their faith in Him. Prayer seems to be an important motivating factor in moving on with life with HIV and in coping not only with HIV but also other stresses of life such as financial insecurity, lack of employment, divorce and ill health. Through prayer and participation in religious activities, the women could reconnect to God. Spiritual belief also promoted emotional stability, an assessment that I note is not far off Williams (1984:92)'s assessment that belief in God can result in a 'transcendence of causality and reconstruction.' In searching for meaning, I contend that these women are actively reworking their biographies through spiritual means. Spirituality offered an explanatory system but also provided the participants with the resources they needed to face an altered situation.

Religious belief enabled all participants to reconstruct and renegotiate life on their own terms. In chapter six, some participants spoke of how their religious faith enabled them to reconstruct their identity so that they were no longer simply mothers and wives but are also women leaders, motivational speakers and counsellors. The

participants wanted to be seen not as HIV positive women but as individuals who can make meaningful contributions to the wider society. I also observed that medication was a particularly important resource in enabling a move towards a new sense of self and hence, a biographical continuity which enabled the women to maintain balance. Medication also helped to promote psychological wellbeing by removing the immediate threat of death. This is in line with a study by the World Health Organisation which has noted that spirituality provides an important coping mechanism by enabling individuals find meanings in their lives. Examples of spiritual coping mechanisms that I observed among the participants in my study include fasting and prayers, reading scriptures or simply attending religious services. Spirituality/participation in spiritual activities provided an important source of social support by giving these women a connection to others in the community.

Faith in a Higher Being enabled the women in my research to attain a renewed sense of self, purpose and hope. Their faith also had an impact on adherence to medication and in fact, some participants saw ART as a miracle from God, hence the importance of adhering to their medication. The experiences of these women also demonstrate that the longer they live with HIV, the stronger their spiritual faith and the more likely they are to adhere to their ARV regime because they understood that it enabled them to maintain good health and with correct adherence, HIV need not be an immediate death sentence. The women in my research made frequent references to their strong spiritual faith in God developing positive coping strategies for living with HIV, a finding in line with other studies which have similarly noted that a belief in a Higher Being enabled people to develop positive coping skills as well as increasing the likelihood of disclosure and active support from their family and church group (Doolittle et al 2018; Arrey et al 2016).

8.4 Synthesis: Overview of conceptual and methodological framework

In my research, I have applied a feminist lens to IPA to draw out the social and cultural factors that have shaped women's experiences of living with HIV. This framework also takes into account individual factors. Applying a feminist lens was useful in enabling me to consider the participants' gendered experiences of HIV. The concepts of biographical disruption and chronic illness can help us explore and

understand the dynamics of women's experiences of living with HIV. When the experiences of the women from this study are synthesised in relation to the social, cultural and other contextual factors that they face, the concepts of biographical disruption and chronic illness offers insights about the everyday life of some Nigerian women living with HIV.

It is this synthesis that has led me, through analysis of the interview data using IPA, to cluster findings into categories that are related to biographic disruption, namely the women testing positive for HIV, the impact and meaning of HIV on the women's lives and how they come to terms with HIV. The synthesis also led me to consider how the conceptual and methodological frameworks can be applied to Nigerian women. The findings chapters (five, six and seven) of this thesis have provided a detailed exploration of the participants' lived experiences with HIV within the context of stigma, poverty and gender inequalities as well as their biographical selves. Applying a feminist lens to illuminate the women's experiences is appropriate in bringing into relief the idiographic approach of IPA in this study. My study also situates the participants' experiences within broader social, economic and historical contexts.

I noted earlier that treatment providers have come up with a simple message designed to encourage people to live with HIV. 'Living Positively' with HIV is presented as a simple and relatively easy process yet this message does not consider the impact of the social, cultural, economic and individual factors on women's lives that affect their experience of living with HIV. The 'Living Positively' message suggests that treatment providers do not always recognise the efforts and strategies that women undertake to manage their lives with HIV. For example, treatment providers encourage women to disclose their HIV status but they do not always acknowledge in more explicit terms that it is not a straightforward process and they do not consider the implications of disclosure for these women. My study has provided a detailed exploration of women's experiences, in order to counter the simplistic notion of 'Living Positively', to demonstrate that living with HIV is neither an easy nor simple process. The treatment providers rely on policies based on western approaches from the global North, which may not necessarily be appropriate for countries in the global South. Women and their treatment providers are caught

between donor driven policies and the reality of their experiences with HIV in a low-income country in the global South. The 'Living Positively' policy is a donor driven policy that does not consider issues that affect Nigerian women's lives such as poverty, gender inequalities, stigma and discrimination and complex family dynamics.

My study revealed a wide range of experiences and found that women valued their relationships with their wider social world and many took steps to protect these relationships. In a society where women are idealized as wives and mothers, HIV positive women have struggled to find their voice and to define themselves as women living with HIV. Although society has devalued HIV positive women on account of their HIV status, women have nonetheless rejected notions of promiscuity and some have demonstrated power and agency in the decisions they make about living with HIV. One example of this can be seen in the context of marriage where those participants who remained together with their husbands/partners who infected them emphasised that it was their own choice to do so; women also understood the risk that came with their husband's infidelity- for example, Ria's experience as in chapter 5.2.1 of this thesis. Another participant decided to advertise for a suitable HIV positive partner on her own terms (Binta) while another decided that she would no longer seek relationships nor companionship with men; instead she would deal with HIV alone (Rabi). These actions demonstrate that despite the gender inequalities and patriarchal tendencies within Nigerian society, women do find inner strengths to empower themselves in ways that are not always acknowledged by the literature, by treatment providers and by policymakers from the global North.

8.5 Contribution to knowledge

Part of my motivation for carrying out this research is due to limited research focusing on Nigerian women's lived experiences with HIV. My contribution to knowledge is a significant one in three important ways. Firstly, my research explores the lived experiences of HIV positive Nigerian women living in Jos, North-Central Nigeria. There are very few studies on Nigerian women living with HIV and no other study, to my knowledge, has explored chronic illness as biographical disruption using

IPA as a methodological framework in a West African female population. Since Kathryn Rhine (2016)'s outstanding monograph which explores the emotional, ethical and material dimension of HIV positive women's relationships with men in Northern Nigeria, there have been few studies on the lived experiences of HIV positive Nigerian women.

Secondly, my research focuses on biographical disruption and applied a feminist lens to explore the experiences of Nigerian women living with HIV. Adding a feminist lens to both IPA and biographical disruption provides an alternative way of exploring the lived experience of HIV positive Nigerian women. During my search of the literature, I found that whilst there was a growing body of research studies that have utilized IPA, there is only a limited number of studies that have focused on the lived experience of HIV positive African/black women and most of these studies have been carried out in the global North and none of these have focused on the lived experience of HIV positive Nigerian women. Therefore, in the light of the paucity of IPA studies on women of African descent, the contribution that I make to knowledge is quite significant, particularly as my research is quite rich in data and brings to life the voices of HIV positive Nigerian women who might not otherwise have had the opportunity to share their experiences of HIV with a wider audience.

On a final note, I also note that my research utilized Bury (1982)'s notion of chronic illness as biographical disruption to highlight and to deepen understanding of Nigerian women's lived experience of HIV. Applying IPA to biographical disruption enabled me to draw out the individual experiences of Nigerian women living with HIV- to the best of my knowledge, I have found that there is no other study that has applied Bury (1982)'s biographical disruption to study either the illness narratives or experiences of Nigerian women or of West African women.

8.6 Future research

My research generated several key areas of knowledge which would benefit from further additional qualitative research, to contribute to a growing body of knowledge about HIV/AIDS in Nigeria, with a particular focus on women. Prior to carrying out my research, I had not considered how HIV affects the marital prospects of young, unmarried HIV positive Nigerian women from the North-Central of the country but my

research found that the experiences of unmarried women are somewhat different from those of married women. This subject would be an interesting area for future research studies to address and it would also be interesting for future studies to explore how unmarried Nigerian women negotiate HIV with emphasis on sex, marital prospects and childlessness. My study also found that married women tend to take the decision to remain married to their spouses who have infected them in the first place, so it would be interesting for future research that could explore the gendered construction of HIV among married couples living in North-Central Nigeria. This study could explore the ways HIV positive couples respond to HIV, treatment, how they negotiate HIV within the contexts of their relationships and the gendered positioning (if any) that they adopt in making sense of HIV. By gendered positioning, I refer to the power dynamics that comes into play when couples try to navigate life with HIV (i.e., notions of masculinities and femininities, distribution of power in a relationship and notions of agency).

Additionally, my interactions with treatment providers and their clients also suggests that the relationship between female HIV positive clients and their treatment providers would be an important one to explore further to compliment my own research; the nature of a future study in this area could explore HIV therapeutic citizenship in the context of disclosure of HIV status, women's utilization of support groups and political activism within the HIV community. For the women who participated in my research, religion has played an important role in providing emotional and psychological support in living with HIV, so this could be an interesting area for further research focusing on the spiritual lives of HIV positive Nigerian women from the North-Central. This further research could apply a feminist lens to construct Nigerian women's narratives of living with HIV and could lend additional focus of their spiritual coping strategies. I note as well from the experiences of the women in my research that many of them had difficulty with their medications- this was particularly the case for the younger unmarried who were still struggling to manage their identity whilst living with what is essentially a medicalised yet stigmatised condition; a future study in this area could explore the embodied experiences of HIV among young women who have shown an intense desire for a cure, how they manage their identities and relationships and the choices they make to negotiate the impacts of HIV. In particular, it would be interesting to know how

young HIV positive Nigerian women position themselves in relation to their disclosure or non-disclosure strategies as part of their embodied experiences of living with HIV.

8.7 Recommendations

The data of the findings presented in chapters five, six and seven demonstrates that living with HIV has consequences for the socio-economic, emotional and psychological wellbeing of the participants. HIV highlights their continued sense of powerlessness, particularly with regards to the wider issues of gender relations and power in Nigerian society. Many were (and still are) unable to negotiate safe sex and many remain in unstable relationships due to social expectations and lack of financial security, though for these women, it was often their own decision to remain in these relationships. HIV has affected how the women view themselves, particularly in the context of their personal, family and social relationships- in other words, HIV has disrupted their biographies. From the information that participants have provided in their interviews, it is clear that several factors contribute to their experience of HIV including social attitudes towards HIV and the low socio-cultural status accorded to women in Nigerian society and it is important for treatment providers to recognise that a one-fit all model may not be suitable for their clients.

There is an urgent need for treatment providers and counsellors to take a more holistic, gender and culturally sensitive approach to counselling that focuses on helping HIV positive women to come to terms with living with a new, altered self. This approach should be geared towards mobilising resources to help women to integrate HIV into their biographies by encouraging women to draw out their own meanings of what HIV means to them. My research also notes that there is a need for more specialized therapeutic intervention, particularly at the initial stages of diagnosis and treatment; as part of this early intervention, counselling would be useful in encouraging women to come to terms with their HIV status through the creation of new values that can be incorporated into their biographies although my research also recognises from the experiences of the participants in the research that coming to terms with HIV is a gradual process that occurs over time. It is recommended that

treatment providers scale up their counselling services to include more trained, professionally educated counsellors who are equipped to provide specialized counselling to help women navigate HIV, something that women like Grace and Irene would have greatly benefited from. I observed during fieldwork that most counsellors I interviewed in this study are workshop trained counsellors who received their training through counselling workshop programmes that were held over the course of 3 days or one week.

It is further recommended that treatment providers should stress on the benefits of support groups. Encouraging women to join support groups would be particularly beneficial for them because it provides them with the opportunity to engage in the HIV community and helps to minimise social and psychological isolation. Only four of the eleven participants in the study participated in support groups and the majority of these non-attendees are unmarried, single women. I observed during fieldwork that treatment providers did not always stress the availability of support groups for women who had recently been diagnosed with HIV and also for those already living with HIV. A key recommendation that emerges from my research is that there is an urgent need for treatment providers to emphasize the importance of support groups for this group of HIV positive women, particularly at the initial stages of diagnosis and treatment. The support group should help facilitate universality, cohesion and a sense of hope for young women by providing an opportunity to meet and engage with other young adults who are also living with HIV. In particular, treatment providers and counsellors should pay additional attention to the needs of poor and uneducated Muslim women who are often unable to access the psychological support that they need in living with HIV. It is further recommended that treatment providers initiate support group meetings on more regular basis rather than just once a month and should have smaller, more focused support groups.

It is further recommended that treatment providers take into account the individual context of each female client and the unique ways in which they experience HIV and work with the client to help them regain a sense of control and personal autonomy over their lives in living with HIV. There is a need for a professionalized counselling service for women who are already living with HIV. Most of the participants in the research require counselling but they were not receiving the psychological help the

needed even though the treatment providers who participated in this study have counselling units that can offer or refer clients for specialised psychological help. The participants in the study were quite eloquent in narrating their experience of HIV, which in turn suggests that storytelling (which is an important way of communicating in Nigerian culture) may be a valuable tool in setting up an effective group counselling therapy that focuses on narratives and hence, is culturally and gender sensitive to the counselling needs of these women. Engaging women to tell their own stories enables them to connect with their emotions, thereby enabling them to grow and discover a new sense of self and personal strength through the connections that they make with their own stories. Storytelling enables the storyteller to achieve self-awareness, recognise their own role in the story that they tell and therefore move towards self-recognition of themselves as HIV positive women. Through self-recognition, women can achieve self-healing. Storytelling is also an empowerment tool that enables women to communicate with their emotional and social self and to achieve power and personal autonomy through their own stories. Storytelling in their own language (Hausa) would be particularly beneficial.

As the women in the study were quite anxious about their future, particularly in relation to their health, stigma and concerns about disclosure, it is recommended that treatment providers create and promote self-management programmes that can address the individual needs of the women accommodate their own particular experience of HIV. For the unmarried women who are keen to get married in the future, their HIV status is a constant source of anxiety, for which in addition to storytelling, therapeutic interventions based on relaxation techniques such as meditation would be useful in helping to alleviate anxiety. It is recommended that self-management programmes be delivered in a number of ways, including through one to one counselling and group therapy.

Finally, given the economic disparities between men and women, HIV positive women are particularly vulnerable to discrimination and poverty, as I observed during fieldwork in Nigeria. It is recommended that treatment providers work additionally to address the socio-economic problems facing HIV positive by strengthening initiatives aimed at creating opportunities for women, including basic skills acquisition programmes such as dressmaking, catering and juice making, hairdressing,

computer skills and food processing- these are areas that have the potential to enable women generate income. The treatment providers in this research already had skills acquisition programmes in place but throughout my stay in Nigeria, these programmes were never initiated even though the experiences of the women in this study suggest that they are keen to acquire skills that would enable to make ends meet and therefore empower themselves financially. Skills acquisition would be particularly beneficial for women like Talatu, Maimuna, Grace, Vickie and Rabi and would go a long way towards alleviating their financial worries.

Conclusion

This research has demonstrated the value of the IPA approach and the use of biographical disruption to explore the impacts of HIV on women's lives. The findings of the research have highlighted the importance of capturing Nigerian women's experiences of HIV through their own voice and the contexts through which these experiences occurs. Ideas drawn from biographical disruption can be applied to varying degrees on the participants' experiences of HIV. In the Global North, HIV is considered a manageable condition but in contexts like Nigeria, living with HIV remains a painful and complex experience. Women living with HIV are pushed to the margins due to their gender, their HIV status and their lack of access to power.

Appendix 1: the participants and treatment providers

The Participants

1. Ria

Ria is a widow, a Christian and mother of two children who was diagnosed with HIV during pregnancy. Ria was born in a small hilly village in Southern Kaduna and moved to Jos when she got married shortly after completing her secondary school education. She gave birth to her first child within two years of marriage. Not long afterwards, her husband abandoned her and their child without warning and she had to move on with her life. Her husband returned more than a decade later, pleading for forgiveness and reconciliation. Ria forgave him but she wanted a divorce. Following intervention from her church, Ria agreed to accept her husband back and she reluctantly resumed sexual relations with him. Ria became pregnant again but she experienced some complications during the final stages of her pregnancy. When Ria registered for ante-natal check-up, she was asked to do some tests although she was never told the nature of some of these tests. Her HIV diagnosis came as a profound shock.

Her husband's denial and lack of concern about Ria's HIV diagnosis left her feeling shocked and betrayed when she confronted him. Ria's husband abandoned the family for the second and final time and the marriage was effectively over. Her husband died soon after but again asked for her forgiveness before his death. She is now left with an unwelcomed and stigmatised condition. Ria says that despite her HIV status, she had forgiven her husband for infecting her. Life was hard and she had financial challenges including difficulty in paying her rent, transportation and school fees for her youngest child.

2. Halimatu

Halimatu is a Muslim and widow who was diagnosed with HIV in 2003 after her husband's death. Halimatu is the eldest child in a family of nine. She grew up in a town just an hour's drive away from Jos. She describes her childhood as a very happy one, growing up with a loving father who married two wives- her mother died

when she was relatively young and her relationship with her stepmother was cordial although they were not close. She had enjoyable and comfortable childhood and did not lack much growing up.

Halimatu got married after completing her secondary school education- her father consented to her marriage with the understanding that her husband would permit her to carry on with her education. Halimatu began a diploma course shortly after her marriage. Halimatu noted early on that her husband was often ill on and off and he explained things away by telling her that he had cancer; she thought some of the symptoms he experienced such as diarrhoea were strange but she did not question him. Halimatu stated that her husband was her first sexual partner and she had never thought to take precautions to protect herself because she trusted him. Within months however, her husband became seriously ill and had to be hospitalised. He died soon after. She was pregnant at the time and was herself very ill. She had to deal with her husband's death, her own pregnancy and illness during what was a traumatic period but her father gave her much needed support, particularly during periods of severe illness.

She was diagnosed HIV positive during the last trimester of her pregnancy; the doctors at first diagnosed TB, which they had suspected might be due to HIV. She felt betrayed by her late husband and thought her life was over. She dropped out of her higher education course and ceased to believe that she could have a future. She also feared for her unborn child's life but her child is negative. Once she began taking ARVs, she began to plan for her future including remarriage, plans to start a business and re-enrolment in school.

3. Irene

Irene is a Christian and a divorcee. She describes a happy family life growing up with her parents and siblings and visits to her ancestral hometown, famous for its numerous springs, lakes and volcanic mountains. Irene was very reluctant to talk about the circumstances surrounding her life before she tested positive. She found out about her HIV status during a routine check as part of pre-marriage counselling. In the early 2000s, some Nigerian churches were so concerned about the spread of HIV/AIDS that they implemented a controversial pre-marriage counselling policy that

included tests for HIV before they would permit couples to marry. Irene and her fiancé were shocked that she had tested positive but his test result was negative.

Despite this, the couple went on to get married but they agreed not to discuss their HIV status with family and friends. There were tensions from the beginning- her husband wanted children but the need to practice safe sex because of her HIV status was a constant barrier to the couple's hopes of having children. The couple also faced questions and pressure from their families about their childlessness. Irene's marriage eventually broke down and the subsequent stress brought about severe illness, which led to hospitalization in 2012. Irene had to start taking ARVs from then on. Irene stressed that until that time, she had remained healthy and had not experienced HIV symptoms. It was only after her marriage broke down that and she moved back in with her parents that Irene told them about her HIV status- they reacted with shock that she had kept her status secret for so long.

Irene admitted to struggling with her HIV status- she had gone back to take another HIV test in order to convince herself that she not HIV positive and was very disappointed to receive another positive result. Irene hold a higher diploma in Public Administration and aspires to a better job, a new husband and children.

4. Maimuna

Maimuna is a widow and a Muslim woman who was diagnosed HIV positive in 2003 after her husband passed away. She got married very young- she does not know when she was born but she thinks she might have been around 14 years old when she got married. She had her first child within a year of marriage but she also lost several children who died from preventable diseases including malaria and typhoid. Maimuna's father died when she was very young and she was her mother's only child. Maimuna was brought up by her paternal uncle. This uncle made the decision to marry Maimuna off to an older man. Maimuna remembers that her uncle never once consulted about the marriage and neither was she given the option of refusing. Maimuna admits that she was initially confused when she moved to her husband's house because she had no knowledge of sex and had no idea about what marriage entailed.

Maimuna thought that she was her husband's only wife, something that is quite unusual in Northern Nigeria where polygamy is a common feature of marital traditions. Maimuna's husband was frequently absent from home due to the nature of his job. Maimuna does not remember the circumstances precisely but she noted that her husband began to fall ill frequently in the early 2000s- her husband's family members often came to take him to hospital and she remembers him taking medication for his condition. She did not understand the nature of his illness, which her husband explained away as fever. She gave birth to her last child in the early 2000s and she noted the child was often sick.

Maimuna lost her child and husband in the same year and she herself fell seriously ill around the same period. Her husband died without leaving much for her and their remaining children and life became a struggle for them, particularly as she did not have means of catering for their needs. Maimuna was unable to describe her emotional reaction to her HIV diagnosis. She remembered however, that the clinic where she received her diagnosis had asked her to come with a male relative, implying that she lacked the capability to make her own decisions about her health. It was only when she received her own HIV diagnosis that she finally understood that her husband (and quite possibly too, her child) had died of AIDS. At the time of this research, Maimuna engaged herself as a petty trader selling snacks to earn money.

5. Cher

Cher is a Christian, married with children and at the time of this study, was unemployed. She holds a Bachelor degree and previously worked as a school teacher. Cher was diagnosed as HIV positive in 2004- in the months prior to her diagnosis, she fell seriously ill and was hospitalised. The doctors advised her to take an HIV test but her husband refused. When the hospital discharged Cher, her doctors gave her medication for malaria and diarrhoea. Cher remained unwell for several months and only realized the nature of her illness when an organisation came to her Church on a Sunday morning to talk about HIV and to encourage members of the congregation to test and know their HIV status. Cher decided to take a test and much to her anguish and surprise, she tested positive.

She particularly found HIV troubling because of the widespread perception of HIV as a sexually transmitted disease. She was very angry with her husband because it was as a result of her own positive test result that she became aware of his HIV status and she feels that he has put her life at risk by not informing her of his HIV status even though he had already started taking medication. By the time she started treatment, her CD4 had dropped to critical levels, which could have led to death if she hadn't started treatment in time. Her domestic life was troubled her; her husband has been unfaithful throughout their marriage which left her feeling bitter and angry. One of her children is severely disabled yet her husband refused to support the child by providing financial support for psychotherapy and special education- this lack of concern left Cher feeling bitter and angry and she was also troubled by financial constraints which left her struggling to feed her household in the absence of financial support from her husband. At the same time, she took the decision to continue with her marriage because she believed in the notion of a marriage for better or worse, something that comes from her Christian faith. Cher is an HIV activist, counsellor and church leader as well as an HIV counsellor who counsel and test people for HIV.

6. Rabi

Rabi is a Muslim, a widow and petty trader who was diagnosed with HIV in 2009. Rabi grew up in a polygamous home; she remarried after her first husband divorced her. Rabi does not live in Jos but prefers to come to Jos to receive her treatment because the main HIV/AIDS treatment provider in her hometown is small and she does not want people to know of her HIV status. She frequently disguises her trip to Jos as business trips. She discovered her HIV status after her second husband died in hospital and his death certificate mentioned an illness that Rabi had never heard of. When she asked a nurse, the nurse advised her that the illness was one of the symptoms of AIDS- Rabi was understandably shocked. She immediately insisted on taking an HIV test to know her status- the nurse tried to dissuade her by pointing out that she had just lost her husband but Rabi insisted on knowing her status.

Rabi admitted that she has never disclosed her status to her children because of stigma and discrimination but she also wants to protect her children from stigma even though they are adults. Rabi made clear from the beginning that she has always been faithful to her husband but she could not be sure of his fidelity to her. In

the beginning, she used to wonder whether he knew of his HIV status but did not bother to tell her though as far as she was concerned, it was pointless dwelling on this issue since he is dead and cannot answer her questions. Her philosophy in life is 'live and let's live.' She also made it clear that now that she is HIV positive, she is no longer interested in remarriage or relationships of a sexual nature.

7. Vickie

Vickie is an unmarried Christian woman who received her HIV diagnosis in 2007 when she was only 17 years of age- she was still in secondary school at the time. Her HIV diagnosis led her to drop out of secondary school. She still lives at home with her family and works as a volunteer for an NGO. She describes a happy life growing up in a religious family who placed strong emphasis on Christian values including respect, honesty and having good morals as such as modest dressing and not engaging in pre-marital sexual relations; her parents did not have much but were determined to give their children the best in life. Vickie refused to discuss the circumstances surrounding her infection but in 2007, she began to fall ill. Her illness started with a persistent cough and she was referred to a government hospital where she was first diagnosed with TB and then HIV.

Vickie was devastated and immediately concluded that her life was over and she failed to complete her secondary school education. A visit by an NGO to her church several years later prompted her towards a public disclosure of her HIV status to her church. The NGO recruited Vickie as a community volunteer, tasked with educating people about HIV and encouraging people to test and know their HIV status and counselling newly diagnosed clients. At the time of the study, Vickie making plans to resume school to complete her education and then enrol in a diploma course; she was also keen to learn a skill. Her strongest desire however is to get married but she recently faced disappointment when the suitor she had hoped to marry decided to marry another woman instead.

8. Grace

Grace is a young Christian and single mother who lost both parents to AIDS- her father during the peak of Nigeria's AIDS epidemic in the late 1990s and her mother

during a turning point when the Nigerian government began rolling out ART, thanks in part to funding from PEPFAR, in 2004. Grace tested positive for HIV in 2006. Grace's mother began treatment for HIV but the shame of her HIV status, the stigma and the negative attitudes from neighbors and her treatment provider overwhelmed her and eventually, she stopped taking her drugs and died of an AIDS-related illness.

When her mother was alive, the responsibility for looking after her fell on Grace, whose education was severely disrupted, as she had to leave school to care for her. Grace likely contracted HIV from her mother, as she did not take precautions. After her mother's death, Grace and her siblings went to live with different relatives who took all her parents' belongings, leaving Grace and her siblings with nothing, something that left Grace angry and bitter against her father's relatives.

Grace has a young child and had to start taking ART when she was pregnant to prevent transmitting the virus to her child. Grace is no longer with the father of her child- the relationship began well and she informed him of her HIV status but once she began pregnant and started receiving ART, his attitude towards her changed and he subjected her to emotional and physical abuse. One day, he simply locked her out of the house and asked leave. Grace moved back in with relatives. These relatives would prefer not to have Grace with them but at the same time, they saw her as useful help with domestic chores. They were not encouraging when she revealed plans to go back to school, as she did not complete education beyond primary school.

Grace tells me that 'living with this sickness is not easy' and once attempted suicide. At the time of this research, Grace had started a relationship with a man who had been assisting her financially and had asked her to marry him although Grace's relatives were opposed to the relationship because he is a Muslim. She also wants to press on with plans to further her education despite their opposition. Apart from her marriage prospects, Grace complained about the lack of opportunities for women in Nigeria- she was unable to complete her education because HIV affected her life. Throughout our encounters, Grace spoke frequently of her parents, admitted that it was the only opportunity she had to speak of them because other members of her family discouraged her from talking about her parents or her own HIV status.

9. Talatu

Talatu is a Muslim woman who lists her occupation as a homemaker. She was diagnosed HIV positive in 2009 and has a discordant husband and an infected child. Talatu is a convert to Islam and her early life was disrupted by religious conflicts between Muslim and Christian communities in her native Adamawa region. Her family moved to Jos in search of safety and security. Talatu did not progress beyond primary level education partly for cultural and financial reasons- her parents died when she was young and she went to live with her elder sister who had limited resources. Her sister was having to train her own children and was not interested in supporting Talatu's education. Talatu married got married in her teens to a Muslim man. Talatu contracted HIV after caring for a close relative who later died of AIDS. At the time, Talatu was pregnant and because she had not taken precautions, she contracted HIV and in turn infected her baby. Talatu was very devastated when she received her HIV diagnosis. Talatu and her husband agreed that Talatu's HIV status would be a secret between the couple alone.

10. Pamela

Pamela is a young Christian woman who tested positive for HIV in 2011. She comes from a mixed religious and mixed cultural background- one parent is a Christian and the other is a Muslim, both from different parts of Nigeria. Pamela says her parents are no longer together and she grew up with her mother who struggled to provide for her. Pamela has struggled with her HIV status and has never disclosed it beyond her mother and a select few. She was also very angry with her ex-boyfriend for infecting her. She had recently began working for a NGO but one of the requirements of the job was to share her HIV status with the wider society, something that Pamela was not quite ready to do outside a trusted circle but it bought her into conflict with the NGO's coordinator. Pamela was being treated in private hospital but she was paying for the same drugs that other women like Cher and Talatu were receiving free of charge and she was having to travel out of town to another city to get her medication. A doctor advised Pamela to enrol for treatment at a government provider, as it would be far cheaper and her condition would be better managed but she refused, as she did not want to bump into people who may know her in a large treatment organisation. Pamela was concerned with keeping her HIV status a secret

and spoke of it in vague terms so that people including her relatives, friends and housemates would not know that she is HIV positive.

11. Binta

Binta is a Muslim single mother and widow who hails from a mixed religious and mixed cultural background- her parent is a Christian from Southern Nigeria and the other is a Muslim from Northern Nigeria. Binta says that cultural differences played a role in her parents' divorce. Binta is a widow, having contracted HIV from her husband and was herself diagnosed in 2012. She found out her husband's HIV status by accident when she came across an unmarked medication bottle. It was after Binta confronted her husband at a time that he was seriously ill that he admitted he was HIV positive- Binta was very devastated, as she understood at once that her health was at risk. Binta went to a laboratory when a technician reluctantly tested her for HIV and confirmed a positive result to her. Despite her anger at her husband, she agreed to remain in her marriage. Binta described how HIV illness took a terrible toll on her husband- the frequent bouts of diarrhoea, having to deal with his insomnia and the depression that followed and how his illness took a physical toll on her because she was constantly cleaning up after him and not sleeping well.

Her husband became aggressive towards her and she described the unbearable loneliness she faced in caring for him and having to hide their HIV status because her husband insisted on keeping it secret from close family members. Her husband was in denial about HIV and had even been duped into paying a private hospital a large sum of money for a blood cleansing procedure which was supposed to drain out his own blood and replace it with fresh, uninfected blood. In the end, his condition worsened and he had to be hospitalized; without warning, he divorced her simply by uttering the words, 'I divorce you' three times according to the prescribed Muslim traditions. Afterwards, he revealed his condition to his own family members and Binta says she was ostracised by family members who believed she had infected him. Apart from her father and an aunt, Binta had still not disclosed the circumstances of her status to her own family- she feels ashamed and feels she would be stigmatised if she were to disclose.

The treatment providers

The study recruited participants from three treatment providers based in Jos:

Treatment Provider A	<ul style="list-style-type: none"> Participants: Irene, Halimatu, Binta
	<p>Part of a wider network of treatment providers fully funded by the Federal Ministry of Health through PEPFAR with additional funding from the Melinda and Bill Gates Foundation and Harvard University. Offers full comprehensive service including antenatal care, clinic for HIV positive children and provides preventive proxphylis. Ella and Ana work as counsellors for this provider.</p>
Treatment Provider B	<ul style="list-style-type: none"> Participants: Ria, Maimuna, Grace, Talatu
	<p>Receives funding from US faith based donors and the Federal Ministry of Health through PEPFAR. Ola works as a counsellor with this organisation</p>
Treatment provider C	<ul style="list-style-type: none"> Participants: Cher, Pamela, Vickie, Rabi
	<p>Is an independent non-government organisation that relies entirely on overseas funding for its operations including payment for volunteers and counselling and testing services. This treatment organisation now acts mainly as a referral service for Treatment providers A and B, following decision to close its own treatment unit due to lack of resources.</p>

Some key differences between the organisations: Treatment Providers B and C have Christian ethos and focus on sex education as a way of reducing the spread of

HIV/AIDS- this includes stressing on behavioural change and abstinence from sex outside of marriage; Treatment Provider A by contrast, has emphasised condom use as an important way to reduce the spread of HIV. As part of their efforts to support people living with HIV, the three organisations have also initiated support groups (although these were not always regular) and have held community outreaches in religious institutions, schools, town squares and marketplaces to provide information and counselling session to create awareness of HIV and to encourage people to test to know their HIV status. During my time in fieldwork, there were already some debates within these organisations about the long-term sustainability of treatment programmes, with overseas donors increasingly calling on the Nigerian government to take on more responsibility for sustaining the treatment of PLWH.

Appendix 2: Cover Letter to Treatment providers for ethical clearance

COVER LETTER

Miss Sophia Mark
Thomas Coram Research Unit
Institute of Education
University of London
12th September 2012

To: Chairman,
Ethical Clearance Committee
[name and address of treatment provider]
Nigeria

Dear Sir,

My name is Sophia Mark and I am currently studying for an MPhil/PhD in the Thomas Coram Research Unit at the Institute of Education, University of London.

I am writing to request your kind permission to carry out a research study on women living with HIV/AIDS. Specifically, the study will focus on women living with HIV and the work of counsellors. I will be carrying out my research under the supervision of [REDACTED] who is a senior researcher at the Institute with a special focus on health and wellbeing and has conducted research studies and training in a number of countries including the UK, South Africa and Ghana. He can be contacted via email: [REDACTED]

I attach therewith for your attention a copy of my research proposal and offer my assurance that this research study will not in any way harm participants. The information provided by participants will be treated in strict confidence and will only be used for my MPhil/PhD. As I am aware that you are very busy, I have compromised the proposal into 4 pages and attach copies of the consent forms for both counsellors and their clients, a copy of the questionnaire that I will use in the study (for my own record keeping) and the discussion guidelines for use with both the counsellor and clients.

Please do not hesitate to contact me if you have any further queries. I can be contacted via email: [REDACTED]

Yours Sincerely
Miss Sophia Mark

Appendix 3: Letter and consent form for participants

Dear Madam,

My name is Sophia and I am currently studying for a PhD in the Thomas Coram Research Unit at the Institute of Education in the University of London. I am carrying out my research on socio-cultural change and the role of counselling in the care of people living with HIV, with particular reference with Nigeria. I am supervised by Dr. Ian Warwick.

My research topic will focus on how people living with HIV make sense of their condition. There are two aspects to this research. The first part will be an interview and the second part will involve you writing a story about your life. The information that you provide in both the questionnaire and the diary will be treated in strict confidence and will not be shared with any one. The information that you provide will be used for this research only and will be destroyed upon completion of this research. The interview will be taped using a tape recorder and will be erased at the end of the research study. It will not be used for any other purpose except this study and the contents of your interview will not be disclosed to any other party.

Once again, I assure you that the information you provide will only be used for this thesis and to protect your identity, I will not disclose your name, your address or any other information about you.

You may stop at any time if you do not wish to continue. Withdrawing your cooperation from this study will not affect your access to any treatment.

Yours sincerely,

Sophia

Your consent

Please could you confirm that you have consented to take part in this research study by marking your agreement X below?

Write 'Yes' beside the letter X below if you agree to take part in this research:

X

Appendix 4: General discussion guidelines with participants

Example of Interview Schedule

Introductory Information

Good morning/afternoon/evening ma, my name is Sophia and I am pleased to meet you. I am a student studying for my PhD at the Institute of Education in London. Thank you for agreeing to participate in this study. Your participation is very valuable and will form an important part of a study on Nigerian women living with HIV. The aim of my study is to understand how women live with HIV. I will be meeting with you to carry out three interviews over the next months.

(Good morning/afternoon/evening ma. My name na Sophia and I dey happy to meet you. I dey study for one university in London. I wan thank you very much say you gree talk to me- he good say make we know how women like you dey with this sickness. I wan talk to you because I wan know this sickness dey do women. madam, I go come meet you say make we talk three times)

Opening Questions

Ina kwanu ma (Hausa for good morning ma); smile and handshake or hug
Kina lafiya? (how are you)?

Thanks for making time for this interview.

This is our first of three interviews. Today, I would like to ask you about yourself generally and we will use the name that we have agreed to assign to you throughout this meeting. I will also be asking you about the first time you found out about your status. You don't have to answer any question you are not happy with. (Today na the first time we go talk. I go dey ask you about yourself and we go use the name wen we agree say you be anytime we meet. I go ask you about the time they tell you say you get this sickness. If you no wan answer any question, make you no answer).

Do you have any questions before we start. This interview will be audio-taped, please could you let me know if you are okay with this? Remember, you don't have to answer any question that you are not happy/comfortable with and you can stop the interview whenever you want to. (You get any questions before we start? I go record this talk, e de okay with you? Remember say we talk say if you no gree answer any question wen you no like, make you no answer. If you no wan talk, we go stop the interview whenever you like).

1. First interviews- getting to know participants- warm up questions

- a. How are you? Where are you from? (how now? Na where you come from?)
- b. Marital status (you get husband?)
- c. How long have you been living in Jos for? (how long you dey stay for Jos?)
- d. Religion and spiritual life- are you a Christian/Muslim? Does your religion have an impact on your life? [if yes, start discussion about religion- does participant go to church or mosque, any role in church or mosque]- (you be Christian or Muslim? You dey go Church or Mosque?)
- e. What do you do for a living? How are you coping with life in general? (you dey work? Na wetin you dey do? Madam, how body now?)
- f. Do you have children? How many? (you get pikin? How many pikin you get?)

2. Finding out status

- a. How did you find out about your status? (How you come know say you get this sickness?)
- b. What made you find out about your status? Was there any illness, etc? if illness then talk more out about the illness- what sort of illness, length of illness (Wetin make you hear say you get this sickness? You dey sick for body? Na wetin be the sickness before dem tell you say na HIV? How long dey sickness worry you?)
- c. How was life for you during your illness? Who looked after you during you illness? What went through your mind when you were ill? How did you feel about this person looking after you? (How long you dey sick for? Na who dey take care of you? Wetin enter your mind when you dey sick and wetin you think about the person wen dey look after you wen you dey sick?)
- d. Were you asked for your consent before you did your test? (you give them permission before them test you or them test you just like that?)
- e. How long ago was this? (what year, month if remembered)- na wen this happen?

- f. Where did diagnosis take place? (Na where you go do your test?)
- g. Who gave the diagnosis? (Na who tell you say you get this sickness?)
- h. How did you react? Were you on your own when they received diagnosis or was someone else present apart from nurse/doctor? Why were you or were you not on your own? (Wetin you do wen dem tell you say you get this sickness? You dey by yourself or somebody come follow to get your test result?)
- i. How are you dealing with your condition now? (how body/condition now?)

Subsequent interviews then focused on the following which were adapted for each participant:

Second Interviews

3. Managing Condition and general well being

- a. What did you know about HIV before you were tested? (na wetin you know about this sickness before them tell you say you get am? Na wetin you do wen them say you get this sickness?)
- b. Currently taking medications? What is your medication pattern? (You get medicine for this sickness? Na wen you go dey take am?)
- c. How often? Feelings about taking medications? Side effects? (Wen you dey take your medicine? Wetin you think about the medicine? The medicine dey worry you?)
- d. Where do you get medications? Are they free? How frequently do you collect your medication? (na where you dey collect your medicine? When you dey collect the medicine? You dey pay money for the medicine? Any problems with medicine?)
- e. Involved in HIV/AIDS support group? (You dey go support group?)
- f. How do you feel in general? (mental, physical and emotional health)- How body well? How condition dey?)

- g. Is there anything else bothering you? How are you coping/deal with this issue? (how life dey with this sickness? Anything dey trouble your mind?)

4. Disclosure and Experience of stigma

- a. Have you disclosed your status? How did you disclose? (You dey tell people about your sickness? How you tell am? Na who you tell)
- b. If yes, who have you told? (if so, na who you tell am?)
- c. How do people react to your status? What was your own feeling about disclosure? How do you feel about your HIV status now? (Na wetin people do wen you tell them? Wetin your mind tell you about this sickness now?)
- d. If status not disclosed, why not? (why you no tell another person say you get this sickness?)
- e. Ever experienced stigma or discrimination? (anybody don run away from you because of this sickness?)
- f. From who? (who be de person?)
- g. How did you feel? (how he dey do you wen somebody run from you because of this sickness?)

Final interviews

5. Debriefing

- a. Future: what are your hopes for the future? How did you feel about participating in this study? Was there anything in this study that was difficult for you? Do you have any questions about the study?

Ethical Approval from the Institute of Education

██████████
Faculty of Children & Learning
Dean of Faculty: Professor Richard Andrews

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██████████



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By Email

Sophia Mark

7 December 2012

Dear Sophia

Ethics approval

Project title: A narrative study of counselling and women living with HIV/AIDS in Jos, Nigeria.

I am pleased to formally confirm that ethics approval has been granted by the Institute of Education for the above research project.

This approval is effective from 24th October 2012.

I wish you every success with this project.

Yours sincerely

██████████

+++++

██████████

Research Student Administrator
On behalf of the Faculty of Children & Learning Research Ethics Committee

cc: Ian Warwick
IOE Research Ethics office

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