AT THE HELM OF HEALTHWORK: THE EXPLORATION OF BIOGRAPHICAL ISSUES IN HIV MANAGEMENT

THESIS
PRESENTED FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

BY

Ayodeji Bayo Ogunrotifa

ROYAL HOLLOWAY, UNIVERSITY OF LONDON
2021

Declaration of Authorship

I, Ayodeji Bayo Ogunrotifa, hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the works of others, this is always clearly stated.

Signed:………………………….

Date:……………………………..

ABSTRACT

This thesis explores the consequences of healthwork on the biographies of people living with HIV in Nigeria. Biography, as Corbin and Strauss (1987) observed, consists of biographical temporality, the body, and the conception of self. This research explores the impacts of healthwork on the biographies of HIV-positive individuals. In this regard, this study unpacks the biographical implications of healthwork on the everyday lives of people living with HIV.

Thirty-two people living with HIV, recruited from two HIV support groups in South-Western Nigeria, were interviewed about their experiences of living with HIV using semi-structured interviews. The data obtained were then analysed using thematic analysis.

Four key findings resulted from the study. First, it was found that healthwork is comprised of practices that HIV-positive individuals undertake around their health to support their treatment regime; these practices include spirituality, counselling, adherence, testing, dieting, concealment, support group participation and internet use. Second, healthwork helped to rebuild and reconstruct the disrupted biographical temporality of HIV-positive individuals by providing continuity and positivity. Third, healthwork helped to construct non-infectiousness corporealities through reassessment, negotiation, minimisation, and demythologisation. Fourth, healthwork helped to foster the empowered self and the optimistic self for HIV-positive individuals who constructed powerless and hopeless selves following diagnosis.

These findings on biographical time, the body, and the conception of self, offer important insights into biographical aspects of HIV management and, thus, contribute to the literature on healthwork, as well as an understanding of HIV management in a contemporary Nigerian context. Overall, this research has demonstrated that healthwork is integral to the personal and social fabric of HIV-positive individuals.

CONTENTS

Chapter One:

Chapter Two: Literature Review

Chapter Three: Methodology

Chapter Four: Healthwork in Nigerian context

Chapter Five: Biographical Time and Healthwork in HIV management

Chapter Six: The body, Corporeality and Healthwork

Chapter Seven: The conception of Self and Healthwork
In HIV management.

Chapter Eight: Discussion and Conclusion

LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGEMENT

The idea of becoming a professional sociologist was forged during my undergraduate days, where interest in pursuing this doctoral programme was intensified. Rather than being discouraged by the tremendous amount of work and demands for creativity, my primary motivation for intending to undertake a doctoral programme in sociology stems from its multiple applications for resolving important societal problems. Therefore, working on this thesis has not only been a valuable and rewarding experience, but the accomplishment of a long-time aspiration and desire. Words are not enough to express my profound appreciation to the people and organisations whose incredible support, encouragement and guidance have contributed to the completion of this dissertation. I will attempt to thank as many of them as possible in order to appreciate the role they played and the contributions they have provided during this research journey.

First, I thank School of Law and Social sciences at Royal Holloway, University of London for providing a partial doctoral scholarship, which covered my tuition fees. I also thank Ondo State Scholarship for their financial contribution towards offsetting part of my living cost during the programme. This financial assistance enabled me to complete this dissertation.

Secondly, I thank my family. To my loving and generous mother—Victoria Oluyemi—who has always been there to back me. The unconditional support of my siblings has been incredible. To my wife (Oluwaseun) and daughters (Oluwatise Olive and Inioluwa Jemima), my love and thanks for all your support through the high and lows of this academic and research odyssey are boundless and unparalleled. I am forever grateful.

Thirdly, I have greatly benefitted from the supervision and support of my erstwhile supervisors—Professor Jonathan Gabe and Dr Alex Dymock, who provided not only guidance and focus for this study, but also laid an intellectual foundation that imbued in me a passion for scholarship and erudition. To Jon and Alex, your wisdom, guidance, and patience have enabled me to understand the demands and rigours of research, and the roles and responsibilities in academic life. The retirement of Jon Gabe and departure of Alex Dymock in August 2019 initially affected and disrupted

my research, but the foundation they laid provided a useful shock absorber that allowed me to forge ahead. I am indebted to Robert Jago and Michelle Webster, who later took over the supervision. Rob and Michelle provided tremendous and valuable duty of care, guidance and focus needed for this study. I am grateful that the critiques, editing and correction provided by Rob and Michelle contributed a great deal towards the completion of this dissertation.

Fourth, there are many friends outside the university, whose moral support and encouragement have contributed immensely to the completion of this programme, most especially Pastor Fstus Olatunde, Pastor Felix Alemeru, Pastor Abraham Ayelabola, Mr Seni Ajai, Mr Olu Abidoye, Anthony Ademiluyi, Yinka Ajayi, David Odumade, and Dr Olalekan Aladesanmi, and the many others whose supports has been invaluable.

Finally, this dissertation is dedicated to Almighty God for his insight, direction, supernatural support, and providence provided during difficult periods. I am grateful to God that this programme finally ends in praise.

CHAPTER ONE

INTRODUCTION

1.1 Introduction

When HIV first emerged in the early 1980s, it was widely thought to be a terminal disease (Montagnier 2002; Simms et al. 2012). However, with the development of antiretroviral therapy (ART) over the last three decades, HIV has now become a chronic illness, where people living with it live longer, improve their health, and profoundly reduce the risk of HIV transmission (Deeks et al. 2013). ART is used in the treatment of HIV infection by slowing down the reproduction rate of the virus in the body (Cohen et al. 2016) and prevents it from developing into Acquired Immune Deficiency Syndrome (AIDS). Therefore, the use of ART stems from the realisation that HIV is a chronic illness that does not have a cure but can be managed over a period (of time). Time is, therefore, woven into the biographical structure of HIV management, such that HIV management is a biographical experience that is structured into temporal essence. In other words, the management of HIV in everyday life is both biographical experiences and revolves around a set of biographical issues.

In this way, it is important to investigate not just the biographical issues surrounding the everyday experience of living with HIV, but also the social context within which such experience is lived and the kind of practices that people living with HIV undertake around their health to complement their treatment in daily affairs (healthwork). This thesis further considers how the findings on healthwork and biographical issues in HIV management can be utilised in developing a framework for patient-centred care and fostering an integrated approach that incorporates patients' biography, history, personal issues, self, and identity issues into a holistic understanding of health and well-being across a global context. This chapter opens the discussion by outlining the motivation to undertake this research (in section two). This is followed, in section three, by a brief discussion on the clinical context of HIV with respect to its aetiology and medical interventions. This would provide further background to the clinical literature regarding HIV/AIDS. The fourth section addresses the changing policy landscape for HIV treatment. The fifth section focuses on the HIV/AIDS situation in Nigeria, specifically Nigeria's HIV epidemic history and the social responses to it. Sections six and seven focus on the social issues around HIV/AIDS in Nigeria, and the aim of the study, respectively. The final section provides an overview of each chapter in the thesis.

1.2 Motivation to undertake this research

This research was inspired and intensified during my previous employment, when I was privileged to witness the benefits of sociological analysis to the understanding of antiretroviral medications use among the people living with HIV/AIDS. Prior to my doctoral enrolment, I worked with a non-governmental organisation (NGO) whose interest in HIV activism was oriented towards the campaign against discrimination of people that lived with HIV (especially within the family, in public, the workplaces, and many other social spaces). The other interest of my previous employer was campaigning for universal treatment coverage for people living with HIV in both rural and urban centres in Nigeria.

Rather than being discouraged by the tremendous amount of work which demanded creativity in my previous job, my drive to move on was propelled when my previous employer won a state research grant to examine the impact of gender on the experience of antiretroviral therapy (ART) used among HIV-positive individuals. As a result, this prompted my desire to undertake this research. As the only trained sociologist in the organisation, I was selected to lead the research as principal investigator. This role gave me the opportunity to negotiate access with two HIV support groups in South-Western Nigeria. Following the ethics approval from these support groups, we held semi-structured interviews with 30 people living with HIV. The interesting aspect of this research's findings showed that the participants were not concerned about gender as far as the experience of antiretroviral medication used was concerned; rather, they were more interested in their body (that is, the effect that non-adherence to the therapy might have on their body). This observation was received unfavourably by the entire research team as it negated the overall aim of the project. In the report, we wrote that, even though gender did not shape adherence to antiretroviral therapy, adherence had profound implications in the way the people living with HIV promoted their health in everyday life (Ministry of Women Affairs 2015).

Following the conclusion of the project, my motivation was to further explore how adherence constituted health promotion in the context of illness, and thus formed the basis of my initial research agenda at Royal Holloway. While reviewing the literature, I observed two issues that recanted my initial research thinking. First, I discovered that positivistic dimensions associated with adherence and health promotion were inconsistent with the disciplinary boundary of medical sociology, which I am interested in. Second, the sociological critique of adherence had shown that adherence represented a narrow dimension regarding the activities and practices that patients undertook around their medications. It was at this point that I began to look beyond adherence and examined other ways through which patients engaged with their medications (most especially, healthwork). This thesis explores healthwork as an important concept to explore HIV management in everyday life.

1.3 HIV/AIDS—Medical Overview

In medical parlance, HIV is a tiny virus that resides in the bloodstream and spreads from one cell to another and remains dormant in the infected person’s body with a mean year of 8 to 10 before the noticeable illness called AIDS occurs (Montagnier 2002). Whenever HIV enters into the body, its first task is to infect the cells of the immune system called CD4 cells and turn the cells into virus factories—where one virus can create millions of itself (Feinberg 1996). The effect of this cell infection is the destruction and weakening of the resistance capacity of the immune system to protect the human body from infections and diseases (Moss & Baccheti 1989). The more cells HIV infects, the greater the impact on the immune system, and the more the deficiency it produces in the immune system (immunodeficiency). The virus thus destroys the ability of the infected cells to fortify the immune system against external attacks. In other words, HIV suppresses the immune system of the infected person and becomes an incurable serious illness over the mean year. The body then loses the ability to fight many opportunistic infections (Enger et al. 1996; Kaplan et al. 1995) and, thus, increases the risk of premature death from illnesses that would normally be successfully treatable.

Within the biomedical model, HIV is a disease condition ‘where disease progression and treatment success are measured by medical technology at a bodily level that is imperceptible to most people’ (Persson, Race & Wakeford 2003: 398). This model reinforces how the quality of life and well-being associated with HIV/AIDS have been defined and measured: positive changes in viral load, body T cell (T lymphocyte) and how ART are able to adequately suppress viral resistance in the body cell, inhibit viral replication and resistance, and the rebuilding of the weakened immune system (Saravolatz et al. 1996; Hammer et al. 1996) after clinical assessment.

HIV develops resistance to its operation by becoming resistant to certain drugs, and subdues the efficacy of the therapy through mutations, thus continuing to reproduce more of itself in the body system (Weiss 1996). The efficacy of ART rests in its ability to prevent HIV from mutating and helps in slowing down the rate at which the virus reproduces itself and the way it spreads from one cell to another (Broder 2010: 2). Despite the efficacy of ART in suppressing HIV mutation, HIV may easily develop resistance if only one form of antiretroviral drug is used. Therefore, it is recommended by the World Health Organisation (WHO) that at least three antiretroviral drugs should be used ‘to maximally suppress the HIV virus and stop its progression’ (WHO 2017: 5). The use of three or more antiretroviral drugs at a time, which has been regarded as highly active antiretroviral therapy (HAART), does help in improving the quality of life and undermining the capacity of HIV to both harm the immune system and make the body more susceptible to infection and sickness. This description of the clinical pathway for HIV management fleshes out the kinds of experience and concerns that HIV-positive individuals might face following the diagnosis and treatment for HIV. This clinical pathway also provides the impetus for a global response in combating the spread of AIDS through changing the treatment policy at an international level, points which are considered in the following section.

1.4 Changing policy landscape for HIV treatment

The spate of AIDS-related deaths, especially among gay men aged between 25 and 40 years old, came in the aftermath of HIV treatment in the early 1990s and has been attributed to the side effects of early treatment that stemmed from overdosing (Fee & Krieger 1993). Subsequently, the AIDS-related deaths in late 1990s have been attributed to the problem of non-adherence by the AIDS patients (Sabate 2003). This biomedical frame, which was at the margin of the global HIV health agenda prior to 1996, gained important traction following the development of protease inhibitor drugs (in 1996) that heralded the beginning of the HAART era. In this sense, the important watershed in the history of HIV treatment through the introduction of HAART facilitated a significant push towards a global health policy on adherence to HIV treatment. Thus, it created the pathway for local and international campaigns to improve the quality of life and for increased life expectancy by international health organisations working on HIV/AIDS. For instance, in the guidelines on ART published by the WHO (2013), it was argued that, for a longer life and therapeutic effectiveness to be achieved, certain suggestions must be complied with. The suggestions were that a high level of sustained adherence was necessary to: suppress viral replication and improve immunological and clinical outcomes; decrease the risk of developing antiretroviral drug resistance; and reduce the risk of transmitting HIV (WHO 2013). As a result, the biomedical model of adherence dominated the global thinking on HIV/AIDS policy and became the bedrock upon which global policy on HIV/AIDS was conceptualised, formulated, and implemented.

The implication of this is the biomedical pre-eminence to assimilate adherence to the treatment imperative where HIV/AIDS is regarded as a disease that requires not only pharmaceutical intervention, but firm adherence to a medication regimen as prescribed. Through the framework of biomedicine, HIV/AIDS was conceived as a global health issue where adherence to a HIV treatment regimen is required: to prevent the virus from multiplying, protect the immune system, and reduce the risk of both drug resistance and treatment failure to those infected. This perspective, which is widely accepted within the global policy circle on HIV/AIDS, has received important policy echo in the Global South (Obi 2009). This has formed the basis in the formulation and implementation of national HIV/AIDS policy in the Global South (ibid). The biomedical frame of adherence, however, provided the basis for the subsequent global policy of using HIV treatment as prevention (TasP) in recent times.

1.4.1 From Adherence to Prevention

Having hegemonised the adherence discourse in both local and global policies on HIV/AIDS, current global attention is shifting away from adherence to the use of HIV treatment as prevention. This shift towards treatment as prevention was orchestrated by the turn of biomedicalisation in a HIV context. Two developments paved the way for the outset of biomedicalisation in the treatment of HIV, which is the transformation of infectious HIV bodies into non-infectious bodies through recent therapeutic advances in antiretroviral therapy (Keogh 2017). These developments are the therapeutic breakthrough that heralded the prevention of mother-to-child-transmission (PMTCT) in 1994 (Connor et al. 1994) and the introduction of highly active antiretroviral therapy (HAART) in 1996. The campaign around these HIV developments culminated in the concerted campaigns agitating towards changing the policy dimension from adherence to prevention. This campaign was orchestrated towards the use of biomedical drugs to prevent HIV infection among people living with HIV (Kippax & Stephenson 2016), or to decrease HIV susceptibility in uninfected people (Caceres et al. 2015b).

The important argument for prevention is that the sites of infection are being altered due to biomedicalisation, while HIV treatment represents an important tool in the management of not spreading the virus, prevention of re-infection and infection of others (Persson 2013). Despite the potentials inherent in the idea of treatment as prevention, it did not attract global attention and was rather confined to the margins of the global agenda. This was due to the preference and wider acceptability of traditional prevention practices such as condom use, sexual abstinence etc.

However, the development of other classes of antiretroviral drugs such as entry inhibitor drugs (CCR5 inhibitors and Maraviroc), integrase inhibitor drugs (Bictegravir, Dolutegravir, Elvitegravir and Raitegravir), and Entry and fusion inhibitor drugs (Atazanavir, Emtricitabine, Fosamprenavir, Darunavir, Etravirine, Rilprivirine, Eviplera, and Enfuvirtide) that were approved by the FDA and EMA between 2002 to 2019, accelerated the therapeutic landscape of HIV treatment (Aidsmap 2019). The combination of fixed-dose pills of two or more antiretroviral drugs into a single pill that is taken once daily, and the medical advances that followed the development of these drugs, compelled medical experts to re-examine the notion of 'treatment as prevention'. Nevertheless, the idea of 'treatment as prevention' that had remained on the margins of global policy started to receive wider attention in 2008 when a group of Swiss HIV experts published the 'Swiss Consensus Statement' (2008). The claim of this group of Swiss HIV experts, that an HIV-infected person on antiretroviral therapy with a completely suppressed viral load is not sexually infectious (Vernazza et al. 2008), added significant push to the agenda, setting treatment as prevention. The argument that 'a HIV-infected person on antiretroviral therapy cannot transmit HIV through sexual contact' (Vernazza 2009: 115) reignited a new sense of hope and promise of how effective HIV treatment can prevent HIV transmission through unprotected sexual intercourse. Despite the rejection of the claims by these Swiss HIV experts on the grounds that it was based on an observation study, and not through clinical trials, the mantra of treatment as prevention gradually gained currency within the global health circle, as it became one of the themes in the workshop on International Treatment as Prevention in 2011 (Adam 2011).

The 2011 International Treatment as Prevention Workshop (organised by the International AIDS Society in conjunction with key international agencies) in Vancouver, Canada (Montaner 2011) demanded that the implementation of treatment as prevention should await further efficacy trials. Following the Vancouver workshop, several medical experts at the WHO considered that HIV treatment is itself prevention and thus proposed a prevention strategy of a 'test and treat' policy in 2015 (WHO 2015). The new 'test and treat' policy[1] of the WHO aimed at reducing HIV transmission by suppressing the virus in those that were infected by the early use of ART. The policy context that underpinned the new 'test and treat' policy was premised on scientific studies that concluded that rolling out universal HIV testing to diagnose all people living with HIV, and the initiation of compulsory antiretroviral treatment regardless of CD_4 count or viral load, can help to reduce the rate of new HIV infections (WHO 2015). The 'test and treat' policy builds on the 2014 WHO's guidance on how a combination of antiretroviral drugs can prevent population groups

---

[1] This 'test and treat' policy based on recent findings from clinical trials showed that early use of ART keeps people living with HIV alive and healthier and decreases the likelihood of transmitting the virus to partners (WHO 2015).

at significant HIV risk (especially men who have sex with men) from HIV acquisition, using pre-exposure prophylaxis (PrEP).

Following the WHO's policy of 'test and treat', the notion of treatment as prevention has now gained currency within the global health circle, as antiretroviral treatments are increasingly being 'considered so effective at viral suppression that they render people with HIV sexually non-infectious' (Persson 2013:1065). This recent currency on treatment as prevention can be observed in the use of antiretroviral drugs like tenofovir/emtricitabine to develop microbicides,[2] pre-exposure prophylaxis (PrEP),[3] and post-exposure prophylaxis (PEP),[4] as antiretroviral treatments are now used for the primary prevention of viral infection. This primary prevention implies that antiretroviral drugs can be used to prevent disease (HIV) before it ever occurs. This helps the healthcare professionals to prevent exposures to hazards that cause disease, and therefore altering unsafe or unhealthy practices and exposures that can lead to HIV infection and increasing resistance to HIV infection, should exposure occur.

Following their use as primary prevention, biomedical technologies in the form of antiretroviral drugs have now been used as secondary prevention, as the discourse of secondary treatment as prevention (TasP) has been promoted through global campaigns around 'Undetectable equals Untransmittable' (U = U) (Eisinger et al. 2019; Okoli et al. 2021). With secondary prevention, antiretroviral drugs are now increasingly used to prevent HIV transmission, by reducing the amount of the virus in the blood to undetectable levels. This indicates that HIV-positive individuals that are taking antiretroviral treatment as prescribed can have an undetectable viral load (which means that the effective antiretroviral drugs can reduce the amount of the virus in the blood to undetectable levels). The implication of this is that undetectable viral load means that the levels of HIV in the body are so low that the virus cannot be transmitted to HIV-negative individuals through unprotected sex.

---

[2] Microbicides are the creams or gels that are applied to the vagina to help prevent HIV infection.

[3] PrEP is use of antiretroviral medications by uninfected individuals to protect or reduce their risk of infection.

[4] PEP is the use of antiretroviral medicines by uninfected individuals to prevent becoming infected after being potentially exposed to HIV.

This latest therapeutic development of utilising antiretroviral drugs as secondary prevention led to a call for the prioritisation of biomedical drugs in HIV prevention (Kippax & Race 2003), which was premised on the comparative advantage of medical science over the social aspect of HIV prevention (such as condom use) following the therapeutic breakthrough that heralded the prevention of mother-to-child-transmission (PMTCT) in 1994 (Connor et al. 1994) and the introduction of highly active antiretroviral therapy (HAART) in 1996. However, such a call was confined to the margin of the global HIV agenda until 2008, when a group of Swiss HIV experts published the ‘Swiss Consensus Statement’. The Swiss declaration, which surmised that HIV-infected individuals with an undetectable viral load for at least six months, with no other sexually transmitted infections and continued adherence to medications, cannot transmit HIV through sexual contact (Vernazza et al. 2008), intensified a renewed call for the use of antiretroviral drugs in the prevention of HIV (Vernazza 2009).

Following the rejection of the Swiss statement on the grounds based on observational studies rather than clinical trials (Young et al. 2019), more recent studies and clinical trials seemed to have validated the claims of the Swiss experts on the efficacy of antiretroviral treatment in the prevention of HIV non-infectiousness (Attia et al. 2009; Donnell et al. 2010; Cohen et al. 2013; 2015; Baeten & Grant 2013; INSIGHT START Study group 2015). In deepening the discourse of secondary treatment as prevention (TasP) around “Undetectable = Untransmittable” (U = U), a group of clinicians, community and HIV organisations and researchers, under the auspices of Prevention Access Campaign, started a social media campaign tagged ‘Undetectable = Untransmittable’ or ‘#U=U’ in July 2016 (Young et al. 2019; Prevention Access Campaign 2016). Despite the media attention and publicity that this social media campaign generated, the campaign was limited to the idea of reducing stigma and fear of transmission. However, the recent PARTNER 2 study conducted to estimate the transmission risk in gay serodifferent partnerships (Rodgers et al. 2019) found that, when HIV viral load is suppressed, the risk of HIV transmission through anal sex is effectively zero. This study was undertaken among 782 serodifferent gay couples that engaged in more than 76,000 reports of unprotected sex. At the end, it was observed and concluded that there were zero cases of within-couple HIV transmission (Rodgers et al. 2019: 2435). This

PARTNER 2 study provides robust and sufficient evidence for gay couples and heterosexual couples that the risk of HIV transmission is effectively zero when suppressive ART has rendered HIV undetectable. This finding supports and corroborates not only the 2016 social media campaign on Undetectable = Untransmittable (U=U), but also the international campaign on treatment as prevention.

Nevertheless, the global campaigns with the scientific message that Undetectable = Untransmittable (U=U) have continued to gain tremendous traction, as parts of the physician communication with patients have now been gradually incorporated into public health messaging (Grace et al. 2020), irrespective of the virologic risk of failure associated with patients, whose viral load have been consecutively suppressed. The current mantra of treatment as prevention has now become the mainstream and it shapes the current agenda on the global policy landscape concerning HIV.

1.4.2 Critiques of treatment as prevention

Even though the treatment as prevention strategy has a great deal of potential in reducing HIV transmission rates (Smith et al. 2011), there are concerns especially among researchers at the WHO that HIV prevention technology is not totally effective (WHO 2013). Also, other biomedical scientists have argued that HIV prevention technology, especially microbicides, pre- and post-exposure prophylaxis (PREP and PEP), and male circumcision, had extremely limited success (Mayer & Venkatesh 2010).

However, a number of social scientific studies on this current development of HIV treatment as prevention have critiqued the biomedical position for attributing individual weakness for non-adoption of prevention technologies when such weaknesses are occasioned by ‘social structures’, such as gender or poverty (Kippax & Stephenson 2012). These scholars noted that reinforcing HIV as exclusively biomedical, without considering widespread social change that can facilitate changes in practice, will be totally unsustainable. Other scholars like Adam (2011) argued that HIV prevention technologies like pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) are unrealistic in contexts such as the Global South, where access to ART is expensive and problematic.

The review of the current mantra of treatment as prevention demonstrates that prevention (like adherence) represents a narrow approach to what HIV-infected individuals do with their treatment. The concept of prevention seems like a public health mantra that seeks to emphasise a positivistic determinant of health, with little or no explanation about the subjective experience of antiretroviral therapy use. What is problematic is that there is another way in which people living with HIV manage their conditions other than just adherence and prevention, which is healthwork (Mykhalovskiy & McCoy 2002). The lack of engagement on healthwork, especially in the Nigerian context, constitutes the overall aim that this thesis will address.

However, before exploring the aim of this study, it is important to map out the context in which this study was undertaken. This research was conducted in Nigeria. In the following section, I will discuss the epidemiology of HIV/AIDS in Nigeria and the uptake of the antiretroviral therapy programme in the country.

1.5 Setting the context: HIV and AIDS situation in Nigeria

HIV/AIDS as a global pandemic disease and one of the deadliest sexually transmitted diseases has had profound economic and social effects, and a large proportion of the general population across the globe has been decimated by it (Feldman 1994). In relation to global indices, sub-Saharan Africa is deeply affected by HIV and AIDS more than any other region of the world. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) report (2010), it was estimated that 22.5 million people were living with HIV in the region, around two thirds of the global total. In 2009, around 1.3 million people died from AIDS in sub-Saharan Africa and 1.8 million people became infected with HIV. Since the beginning of the epidemic, 14.8 million children have lost one or both parents to HIV/AIDS (UNAIDS 2010).

The most obvious effect of this crisis has been illness and death, while its impact is far reaching (households, schools, workplaces, and economies have also been severely affected). Life expectancy, which has achieved the highest proportion in the developed countries in the last two decades, has been on the reverse in many of the worst hit countries such as Botswana, Lesotho, Malawi, Mozambique, South Africa, Swaziland and Zimbabwe (UNAIDS 2005). Nigeria, the most populous black country in the world, with an estimated population of more than 170 million inhabitants, has been grossly affected by HIV/AIDS. By the end of 1999, it was estimated that the proportion of people living with HIV/AIDS accounted for more than 5.4 percent of the population. This suggests that, with an estimated number of 3.5 million people living with HIV/AIDS, Nigeria 'is home to one out of every 11 people with HIV/AIDS worldwide' (Reis et al. 2005: 744). The UNAIDS official HIV report on Nigeria revealed that there are more than 227,000 cases of new HIV infections, 3.5 percent of adult HIV prevalence, 4.1 percent of infection rate of young people between the ages 15-24 years, and approximately 180,000 AIDS deaths in 2015 (UNAIDS 2015). Thus, it represents the second largest number of a HIV-infected population in sub-Saharan Africa after South Africa. More than 2 million people have been killed by the AIDS epidemic in Nigeria, as 1.7 million children have been orphaned, and more than 300,000 people are infected yearly (Smith 2014). Nigeria's vulnerability to the HIV pandemic can be attributed to a multiplicity of factors such as early sexual debut, multiple partners, extramarital infidelity, inconsistent use of condoms, and homosexual practices (Babalola 2007; Smith 2007).

However, the HIV/AIDS situation cannot be fully understood without addressing a wide range of issues associated with its emergence and the responses (government, social and cultural) to HIV in the Nigerian context. These issues coalescence around: Nigeria's HIV epidemic history; the social issues around HIV/AIDS in Nigeria such as HIV and the body; discrimination and stigmatisation; HIV and religion. Without the exposition of these issues, there would be a tendency to misunderstand the nature of the Nigerian situation and response. These issues will now be discussed as follows.

1.5.1 Nigeria's HIV epidemic history

Nigeria, as the most populous country in Africa, is home to the third largest number of HIV prevalence in the world (Aliyu et al. 2010; UNAIDS 2020). When HIV was reported in Nigeria in 1986, it was dismissed as a foreign disease that would not have any health impact on Nigerians (Balogun 2010). There was no preparation for the likely outbreak of the HIV pandemic in Nigeria and across Africa. This scepticism or official denial of the presence of HIV can be located within the broader context of African AIDS discourse. Without first delving into the discourse surrounding HIV/AIDS within the wider context of the global imagining of Africa, understanding Nigeria's epidemic history would be incomplete. Therefore, discourses about HIV/AIDS in Africa, as Chin (2007) noted, cannot be merely studied as a biological or medical issue that is devoid of economic, political, social and historical processes.

Nigeria, together with most African states, became independent in the 1960s. The attainment of flag independence was compounded by great expectations among the citizens of these newly independent African nations, who were eager to put behind them the dehumanising experiences of colonialism and began a new slate for African development, especially when 'national resources were now in the hands of national leaders rather than those of their former colonial rulers' (Mulwo et al. 2012: 569). However, this sense of optimism was short-lived as the new African political elite used the existing state structure to retain power perpetually, muzzle the voice of dissent and intimidation of political opponents, and engage in a one-party dictatorial regime. The resultant effect of this culminated in electoral fraud, violence and clampdown against the opposition, repression against civil society and the press, and unsustainable political and constitutional crisis in African states that resulted in the long interregnum of military coups and intervention in the polity between the 1970s and 1980s. With widespread disillusionment and political instability, most states were grappling with the burden of famine, disease, poverty, failed state institutions and crippled health facilities. Because of these factors, Africa struggled to overcome most of the health challenges in the 1970s and 1980s, but managed to keep smallpox, polio, and some serious diseases under control (Jamison et al. 2006). The emergence of HIV/AIDS in the early 1980s compounded the situation. These economic, social, and political imbroglios could partly explain the profound denialism and silence that pervaded the early African responses to the HIV epidemic.

Furthermore, there are two other factors that characterised the early African responses to the HIV epidemic, and they are the contestations of the origin of HIV/AIDS, especially in the1980s, and the differences in the aetiology and pathology of AIDS between African and Western perspectives. First, the contestations of the origin of HIV/AIDS within the African health discourse stemmed from the controversial discourse on the African origin of HIV/AIDS. Within Western scientific discourse, it was believed that early cases of AIDS were found in Congo in the 1950s, where a group of chimpanzees lived. The scientific evidence demonstrated that simian immunodeficiency viruses (SIVs) identified in certain species of African apes and monkeys were similar to HIV-1 or HIV-2 (Hladik & McElrath 2008; Hooper 1999). Hooper (1999) argued that ‘HIV spreads from SIV-infected chimpanzee kidney cells which were used to culture polio virus cell lines for vaccination programs in Africa in the 1950s’ following hunters’ contact with the chimpanzees. This view was, however, contradicted following the outcome of an examination of left-over stocks of the polio vaccine by independent laboratories, which found no evidence of HIV or SIV. Surprisingly, it was further revealed that monkey cells, and not chimpanzee cells, were used (Worobey et al. 2004; Plotkin 2001). The appalling Western narrative was that primitive lifestyles of exotic Africa had largely remained unchanged over time, and that, through such primitive lifestyles and practices, the virus (HIV) was transmitted from ape to man due to blood in uncooked monkey flesh (Crewe & Aggleton 2003: 143). This distorted attempt at racialising the origin of HIV drew widespread reactions and discontent from a number of African academics and opinion leaders, who questioned ‘how the origins of a disease that was initially diagnosed among white American “homosexuals” came to be associated with Africa’ (Kagaayi & Serwadda 2016: 188). For instance, scholars like Chirimuutas (1987) challenged the racist attempts at blaming the (black) African people for the spread of HIV and argued that racialising the origin and discoveries of AIDS was part of a continuation of a neo-colonial narrative, aimed at portraying the negative image of Africa. With ‘HIV/AIDS as Africa’s face of disease’ (Mulwo 2012: 570), racialisation and racism have been socially constructed as the important marker of the carriers of illness, infection, and death, which HIV/AIDS represents. Crewe and Aggleton (2003) argued that the global response to AIDS has been shaped and defined by race and racial descriptions since the start of the epidemic, which were aimed at portraying Africa as a dark and exotic continent that was responsible for the emergence and source of the HIV epidemic.

The second is the differing perspective on the aetiology and pathology of AIDS in African and Western discourse. Frank (2009) argued that frameworks and parameters to categorise and pathologise AIDS as an illness in the earliest stage of the epidemic stemmed from Western understanding of the illness. This Western aetiology, which rejected African pathology of AIDS as a disease of poverty, defined AIDS as a sexually transmitted disease that drew on 'on colonial stereotypes of perceived African sexual excess' (Frank 2009: 522). This Western aetiology, which was predicated on biomedicine/biomedical understanding, was derided by African medical experts for being used to contain, control and categorise African bodies as diseased and contagious, while Western bodies are regarded as civilised and strong (Vaughan 1991; White 2000). This suspicion against Western biomedical discourse on AIDS is rooted in post-colonial resistance and deconstruction of African bodies or patients as objects to be categorised, measured, scrutinised, and studied. Furthermore, Frank (2009) noted that Western aetiology of AIDS is more individualistic in orientation, such that AIDS was conceived as a biomedical problem that was restricted to individuals, and that the affected individuals need to 'be controlled by changing individuals' behaviour or by neutralising individuals' risk, either through abstinence or safer-sex practices' (Ibid: 523). This conception of AIDS from biomedical discourse contrasts with African aetiology that articulates more holistic or culturally oriented approaches to illness and misfortune, material inadequacy and social instability (Igun 1988). Therefore, African medical experts at the time believed that it was the Western aetiology of AIDS that shaped international HIV/AIDS policy, which tends to impose Western perspectives on others by global health agencies, without taking the localised context of sexuality into consideration.

In this sense, the Western biomedical stance inhibits an understanding of how the social organisation of sexuality, sexuality's reproductive and kinship-building, together with structural inequalities such as poverty, intersect with culturally shaped ideologies to account for the aetiology of AIDS in an African context (Hirsch 2009). By conceiving AIDS as a biomedical problem, the AIDS policy response that can be drawn from culturally shaped policies, and public health planning to control sexuality, as they have in the past and were rooted in African customs, are labelled and regarded as 'barbaric' or 'repugnant' (Frank 2006).

Throughout most of the 1980s, the negative racial colouration/stereotype, which underpinned the global stigmatisation and discrimination against people living with HIV/AIDS, especially those from Africa, together with the socio-economic and political crisis in Africa and contrasting aetiology of AIDS, culminated in AIDS denialism. The consequence of denialism was a lack of serious and concerted efforts on the part of government officials and healthcare workers to launch HIV/AIDS prevention programmes during this period.

AIDS denialism, in my view, was the fallout of the attempt to push back against racial description, by affirming that Africans cannot be affected by an alien disease that emanated from outside Africa. The useful case in this regard was the Nigerian response to the HIV/AIDS situation. The history of the HIV response in Nigeria can be situated around the government policy history of its existence. This policy history can be categorised into three broad themes: the age of denial, the age of intervention, and the age of 'pharmaceuticalisation'. The epochal period of intervention seems more important in the development and formulation of an appropriate response to HIV than that of denialism and passivity. The subsections below will now focus on each of these separately during the period of policy history in Nigeria regarding HIV.

1.5.2 The age of denial (1981–1986)

The epidemiological history of HIV in Nigeria ensued in 1985 when the first two cases of HIV/AIDS, which included 'a 13-year-old sexually active girl and a female commercial sex worker from a neighbouring West Africa country' (Balogun 2010: 167) were reported. There was official denial of the presence or discovery of HIV/AIDS in Nigeria. In fact, the news of the first two AIDS cases was received with scepticism, doubt and disbelief by the whole country, as AIDS was perceived as the disease of American homosexuals (Awofala & Ogundele 2016). Therefore, the period between 1981 and 1986 was characterised as the age of denialism, where the sceptical public and the government officials believed that HIV/AIDS was a foreign disease (Setel 1996) that was associated with modernity and social changes that came about during the aftermath of urbanisation, globalisation, and development, and as such could not affect Nigerians (Smith & Mbakwem 2010). When these cases of the Nigerian HIV/AIDS phenomenon were reported at an international conference in 1986, the dominant impression within the government and public sphere was that HIV infection occurred because of deviant and stigmatised behaviours such as homosexual practices, drug use, prostitution, as well as sex outside marriage and promiscuity (Adeokun et al. 2006) among gay men in Western society.

The cases of HIV that were first observed in Lagos and Enugu in Southern Nigeria began to spread to other cities in the country. HIV/AIDS is believed to have spread from the Southern part of the country to the Northern part (Balogun 2010: 167-8). The launching of the First Medium Term Plan (MTP1) in 1989, which remained operational until 1994, facilitated the introduction of the National HIV Sentinel Survey in 1991 (Mervis 2012). Through the National HIV Sentinel Survey, it was revealed that the North-Central state of Plateau had the highest HIV prevalence by state by 6.2%, 8.2% and 11.0% in 1991/1992, 1993/1994 and 1995/1996 respectively (Federal Ministry of Health 1998). With more cases reported, the disease continued to spread in Nigeria. In terms of the geographical spread, the HIV epidemic in Nigeria is complex and varies across different regions and states. For instance, in some regions and states, the HIV epidemic is more concentrated in urban centres than the rural ones, while in other regions it is more prevalent in the rural areas than the urban centres.

According to The National Agency for the Control of AIDS (NACA) report (2021), there have been variations in the prevalence of HIV/AIDS high-risk states, as Akwa-Ibom state in the South-South Zone had the highest HIV prevalence in the country with 5.6%, while other states like Benue, Rivers, Taraba, and Anambra have HIV prevalence rates of 4.9%, 3.8%, 2.7% and 2.4% respectively. It is important to state that the HIV/AIDS prevalence in Nigeria between 1986 and 2007 revealed an urban to rural pattern. However, recent data shows that six states in Nigeria account for 41% of people living with HIV, and these states include Akwa-Ibom, Benue, Kaduna, Kano, Lagos, and Oyo at the end of 2016 (NACA 2017), while HIV prevalence, which stands at 5.5%, is the highest in the South-South region of the country, and lowest in the southeast region with a prevalence of 1.8%. Overall, HIV prevalence is higher in the rural areas (4%) than in urban ones (3%) at the end of 2014 (NACA 2015), while the NACA (2020) report shows that HIV/AIDS was more concentrated in the urban centres than the rural areas.

However, the overwhelming proportion of those living with HIV reside in the cities where the risk of unprotected sex is extremely high. Nigeria’s vulnerability to the HIV pandemic can be attributed to a multiplicity of factors such as early sexual debut, multiple partners, extramarital infidelity, inconsistent use of condoms, and homosexual practices (Babalola 2007; Smith 2007). Furthermore, the epidemiological records from 1986 to 2007 revealed that HIV/AIDS was more prevalent among young people in the 25–29 age group. In terms of gender distribution, HIV/AIDS prevalence was observed among females rather than males in both rural and urban centres. Several factors were attributed to females' vulnerability to HIV/AIDS rather than males, and such factors include traditional belief system, low level of education and awareness, high level of poverty, sex abuse, involvement in commercial sex work and intravenous drug addiction (Cohen et al. 1994; Stine 2000).

The subsequent spread of the disease deconstructed the myth of AIDS denialism and the assumptions that underpinned it, and thus prompted the government officials and health workers to reconsider it as being a deadly and fatal disease. The continuous spread of HIV from 1986 was the catalyst that unravelled the reality of HIV/AIDS, and compelled government officials and policymakers to a 'hurried' intervention and development of appropriate responses to the HIV situation. This government intervention marked the end of AIDS denialism. Moreover, a few policy actions and programmes that characterised government intervention will be discussed in the next section below.

1.5.3 The age of intervention (1986–2001)

Most of the HIV/AIDS response in the early period of the HIV epidemic was shaped by government officials and healthcare workers. The age of intervention was the period when the Nigerian government initiated and formulated a wide range of policy actions, programmes, and activities, designed to curb the spread of HIV among the population. This intervention consisted of a wide range of strategies initiated to produce behavioural changes of Nigerians that were sceptical or regarded AIDS as a foreign disease. The Nigerian health sector led by the Federal Ministry of Health developed the appropriate intervention and coordinated the national responses to the HIV/AIDS epidemic in Nigeria. The onset of HIV policy intervention started when the then Federal Minister of Health, Professor Olikoye Ransome-Kuti, understood the danger and severity posed by HIV amid public scepticism. He quickly admitted and acknowledged that there was a problem, developed measures and strategies towards curtailing the disease at its prime, and established the National AIDS Advisory Committee in 1986—a body that developed a comprehensive national policy on HIV/AIDS (Orubuloye & Oguntimehin 1999).

Orubuloye and Oguntimehin (1999) further deliberated that a lukewarm response from the government to take control of HIV/AIDS, in the age of intervention, was unconnected with a change of government through a military coup d’état and the consistent policy somersaults on the part of successive regimes in Nigeria, as well as the withdrawal of international organisations and their HIV funding due to sanctions by the military regime. The following year, the committee was later replaced by the National AIDS and STD Control Programme (NASCP) whose expanded scope of operation was articulated in the first Medium Term Plan (MTP 1), which was later reviewed in the second Medium Term Plan (MTP 2) that ended in 1997.

In 1998, the second Medium Term Plan (MTP 2) was initiated by the federal government of Nigeria, with a view to reappraising the past government’s interventions, policy lapses and its shortcomings. The major thrust of the plan was to provide advocacy at the highest level for HIV/AIDS prevention and control, and to advocate co-operation, collaboration and support from all agencies and bodies for successful Petroleum Trust Fund-assisted HIV/AIDS prevention and control programmes (Adeokun et al. 2006).

As part of the second Medium Term Plan (MTP 2), the national government through the Federal Ministry of Health, Federal Ministry of Information as well as Federal & State Government agencies such as National Action Committee Against AIDS (NACA), engaged in an aggressive public awareness campaign and sensitised the public on the dangers of the HIV/AIDS pandemic. These awareness/sensitisation campaigns were undertaken through ‘television and radio Jingles, talk-show programmes and drama presentation, Newspaper and Magazine adverts, posters, outdoor billboards, pamphlets and handbills. Others include door-to-door campaigns, musical concerts and road-side shows’ (Raj 2008: 216). Other channels of sensitisation campaigns included schools, churches/mosques, and among different groups such as farmers, market women, artisans, and the civil service, as a way of facilitating behavioural change in the population and reducing the HIV prevalence rate. As Keating et al. (2006) noted, these sustained campaigns were orchestrated through specialised and non-specialised non-governmental organisations (NGOs), Labour-Based Organisations (LBOs), Faith-based organisations (FBOs), parents, teachers and other bodies. The HIV sensitisation awareness cut across every segment of the Nigerian society from rural to urban centres and were replicated across the 36 states of the federation and F.C.T. Abuja. The awareness campaigns were geared towards minimising risky behaviours around the notions of safe sex, abstinence, unsafe blood, risky behaviours, stigmatisation, condom use, mode of HIV transmission and other HIV prevention strategies against the spread of HIV/AIDS in Nigeria (Bankole & Mabekoje 2008; Kadiri et al. 2014). The awareness campaigns were also directed towards advising the public on HIV testing as a factor and guidance for marriage. In this regard, people were advised through awareness campaigns to undergo HIV testing before committing to sexual relationships and marriage.

Other aspects of the second Medium Term Plan included the following: to 'develop and articulate a plan of action towards effective HIV/AIDS prevention and control throughout the nation; to create a forum for exchange of experience by involved persons and to streamline HIV/AIDS intervention' (Adeokun et al. 2006: 214).

Source: *Google Map of Nigeria*

The outcome of the national conference on HIV/AIDS ushered in a comprehensive update of national policy on HIV/AIDS in Nigeria that aimed to campaign for 'behaviour change, treatment, and prevention of sexually transmitted infections and promotion of condom use within the context of abstinence and fidelity' (Aguwa 2010: 211-212).

This national response to HIV was sustained in the post-military era. When Nigeria returned to being a democracy in 1999, there was a renewed hope in the commitment of the civilian regime to act decisively against the disease that was eating deep into the general fabric of the Nigerian population. The new civilian regime was able to convince the international partners (international organisations) and agencies to donate to the cause of eradication of HIV/AIDS in the country. The new civilian regime developed and articulated a new policy which led to the establishment of NACA in 2000 to effectively implement the resolutions of the 1998 National Conference on HIV/AIDS and STDs Control and Prevention at a national level, and at the states and local government levels (SACA and LACA).

The primary objective of establishing the NACA was to coordinate the broad spectrum of the AIDS response that interfaces with all the stakeholders involved in the fight against AIDS in Nigeria. This would help to centrally control and oversee policies, programmes and projects directed at the AIDS issue, provide leadership, and monitor the progression of the epidemic.[5] In 2007, the act establishing the NACA as a fully-fledged independent government agency was passed by the Nigerian parliament, with the mandates to ‘formulate policies and guidelines on HIV/AIDS, advocate for mainstreaming of HIV/AIDS intervention into all sectors of the society’.[6] Other functions of NACA, according to the act, are to plan and coordinate activities of the various sectors in the strategic framework of the national response to facilitate the engagement of all tiers of the government and all sectors on HIV/AIDS prevention, care, and support (NACA 2010).

Since its incorporation as a statutory government body, the NACA has formulated and implemented a series of policies and guidelines encompassing HIV/AIDS financing, building networks and partnerships with global institutions and organisations. The NACA has also liaised with civil society groups, religious institutions, and non-governmental organisations (NGO) with a view to expanding treatment access to other areas hitherto uncovered, thereby providing wider coverage among the infected population.

As a statutory government body, the NACA has provided a multi-sectoral strategy and relationship with other HIV governance structures of states and local governments with a view to providing effective coordination and rapid response to HIV/AIDS at both state and local government levels. As far as the HIV situation in Nigeria is concerned, the most strategic national response to HIV and AIDS is the establishment of the NACA, whose achievement can be seen in areas of advertisement and enlightenment campaigns, and the articulation of the ART programme in Nigeria. Apart from the urban centres, most rural areas are now enlightened about HIV in terms of awareness on healthy and safer sexual behaviour, HIV counselling and testing, and increasing awareness and treatment with antiretroviral therapy (NACA 2018).

---

[5] For more details on the objectives of establishing the NACA, see the history of NACA available at https://naca.gov.ng/history-of-naca/

[6] See the NACA’s 2011 Annual progress report, available at https://naca.gov.ng/wordpress/wp-content/uploads/2016/11/NACA-2011-ANNUAL-REPORT-FINAL-DRAFT_06062012-2011REPORT.pdf

The policies and programmes initiated during the age of intervention helped to prevent the spread of HIV through educational and awareness campaigns, designed to foster behavioural changes to the sceptical public. The saliency of the age of intervention in the annals of HIV policy history in Nigeria, compared to the age of denial, can be seen in the foundational basis in which the provision of a free antiretroviral therapy programme and the pharmaceuticalisation of public health was later situated.

1.5.4 The age of the pharmaceuticalisation of public health

The notion of the ‘pharmaceuticalisation of public health’ was first articulated by Biehl (2004) to describe how countries in the Global South prioritised and framed the free distribution of antiretroviral drugs to people living with HIV, as needed to protect the public health of their citizens. Using Brazil as a useful case study, Biehl observed that the provision of free antiretroviral drugs to registered to people living with HIV in Brazil had made public health increasingly pharmaceuticalised around the reduction of AIDS-related mortality and improvement in the quality of life for people living with HIV (Biehl 2004; 2006;2008). Following the Brazilian model, Nigeria introduced a free antiretroviral therapy programme in 2002 to registered people living with HIV. The onset of the ART programme is the onset of the pharmaceuticalisation of public health in Nigeria.

From the mid-1980s to 2001, the use of ART received less attention following the high cost of medication that excluded many people (HIV-positive individuals) who needed it. In 2002, a reprieve came for many infected HIV people when the ART programme was formally established by the Nigerian government. The ART programme was launched in collaboration with different donor agencies, civil society, and national and international agencies, who provided the logistics for the successful uptake of the programme.

The objective of the ART programme is to treat more than 10,000 people with antiretroviral therapy within the first year in 25 antiretroviral centres throughout Nigeria, and improve the quality of care in the antiretroviral treatment programme by training more than 100 doctors, 100 nurses and 100 counsellors within the first year of its establishment (Monjok et al. 2010). Other aims of the ART programme are: to strengthen the involvement of people living with HIV and AIDS in the antiretroviral treatment programme; improve coordination between the public and private sectors; and remove barriers to the treatment of low-income people living with HIV and AIDS by making laboratory testing free of charge (Meloni et al. 2016). Under the government programme, the cost of the first-line drug regimen was subsidised to the tune of US$ 368 per person per year, whereas in the private sector the cost was estimated to be US$ 3000 per person per year. Antiretroviral drugs, in the sum of US$ 3.5 million, were procured from India and offered at a subsidised rate of US$10 per person (Idigbe et al. 2005).

According to WHO (2011), the first set of antiretroviral drugs (AVG) regimen to be available in Nigeria were Lamivudine, Stavudine and Nevirapine—which were used for the treatment of adults and adolescents. Also, Lamivudine and Stavudine with either Nevirapine or Efavirenz became the first set of drug regimens used in the treatment of children infected with the virus. At the outset, the programme was divided into two phases. The first phase consisted of providing treatment for 250 patients in each of the 25 ART centres, and each patient was asked to pay a monthly treatment cost of N1,000 (£3) to cover the cost of regular laboratory tests (Odutolu et al. 2006). The successes recorded in the first phase enabled the government to extend the programme to the rest of the infected population (over 4,000 patients). Following the successful launch of the programme and the benefit accrued to the recipients, more HIV-infected persons were recruited into the programme in 2003.

Due to the large number of patients recruited, the programme was marred by serious setbacks and shortcomings as there was a shortage of drugs. It was widely reported that many patients were taken off drugs for up to three months because of a lack of supply, which resulted in a huge increase in the non-adherence rate and serious resistance to the drugs from the virus (Monjok et al. 2010). The ART programme was later resumed following the procurement of another round of US$3.8 million worth of drugs. In 2004, the ART programme was reviewed by the Nigerian government following the administrative weaknesses, logistics problems, and capacity bottlenecks that marred the third phase of the programme. The outcomes of the review paved the way for the establishment of the Nigerian National Response Information Management System in many states of the federation. Other outcomes of the review include the following: the launching of the National Antiretroviral Scale-up Plan in December 2004, and the approval of the Health Sector Strategic Plan on HIV/AIDS 2005–2009. The major thrust of the National Antiretroviral Scale-up Plan was to ensure that 250,000 people living with HIV/AIDS were put on the ART programme by June 2006. To achieve this ambitious objective, ART treatment centres were extended from 25 to 63, while funds were made available for the new centres to provide antiretroviral therapy services. These services include voluntary counselling and testing, condom distribution, mother-to-child transmission services coupled with treatment, and care and support for people living with HIV/AIDS.

The financial assistance from bilateral and multilateral agencies such as the United States President Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the World Bank has contributed a great deal towards expanding the provision of ART to many HIV patients that has been hitherto left uncovered free of charge. In 2006, the establishment of 41 ART treatment centres greatly helped in the distribution of a free supply of ART to many patients.

Despite the massive scale-up of ART treatment from 81,000 people to 198,000 by the end of 2007, it was reported that only 15 percent of HIV-positive persons had access to ART treatment (Federal Ministry of Health 2007). With more financial support from its partners, the Nigerian government had been able to scale up the number of ART enrolment from 198,000 to about 300,000 at the end of 2009 (UNAIDS 2009). In comparing the enrolment success achieved in 2009 with the enrolment target articulated in the National HIV/AIDS Strategic Framework for 2005–2009, it can be observed that the enrolment recorded in 2009 is 49 percent less when compared with the ART enrolment target of 80 percent that was projected for 2009. By the end of 2016, a total of 853,999 people living with HIV (both children and adults) were receiving antiretroviral treatment out of over 3 million people living with HIV (NACA 2016). This information revealed that over 28 percent of people living with HIV have access or are currently receiving antiretroviral treatment in Nigeria. However, the number of people living with HIV having access to antiretroviral therapy, up from 360,000 people in 2010 to more than 1 million people at the end of 2018, with new estimates revealed that ‘more than half of people living with HIV still do not have suppressed viral loads' (UNAIDS 2019). However, information on ART enrolment between 2019 and 2021 is not available at the time of writing this thesis.

The slow progress in achieving ART enrolment targets stems from a multiplicity of factors such as a shortage of healthcare personnel, weak clinical and diagnostic capacity, poor data management system, and restriction of treatment care to secondary and tertiary level hospitals (Odafe et al. 2012; NACA 2010; Van Damme 2006; Lawn et al. 2005; Coetzee et al. 2004). Because of this, a comprehensive review of the National HIV/AIDS Strategic Framework for 2005 to 2009 was undertaken by the Nigerian government, who revised the framework and extended the treatment goals and targets from 2009 to 2015 (NACA 2009).

However, significant improvement was witnessed between 2010 and 2011 in HAART enrolment and with the HIV prevalence rate in Nigeria. Official figures obtainable from NACA showed that the HIV prevalence in the country, which was 4.6 percent in 2008, had declined to 3.4 percent in 2017 (NACA 2017), while the number of people living with HIV/AIDS receiving antiretroviral drugs increased from 230,000 at the end of 2008 to over one million at the end of 2018 (UNAIDS 2019). There was also an increase in the number of ART treatment centres from 296 at the end of 2008 to 820 at the end of 2016 (Tocco 2017: 76). Recent data released by UNAIDS revealed significant improvement in the fight against HIV/AIDS. It was revealed that AIDS-related deaths decreased by 35 percent in 2019, while 89 percent of people living with HIV are now accessing antiretroviral treatment (UNAIDS 2020). The national HIV prevalence among adults aged 15–49 years reduced from 2.8 percent to 1.4 percent at the end of 2018, with an estimated number of 1.9 million people living with HIV in Nigeria (UNAIDS 2019).

Despite these remarkable accomplishments, much effort is still needed on the part of the Nigerian government and other bilateral and multilateral partners in ensuring that over 600,000 adults and 262,000 children that are currently out of antiretroviral treatment coverage are recruited into the programme. However, the important consequence of the pharmaceuticalisation of public health vis-à-vis the introduction of the ART programme in Nigeria is the enactment of what Ecks (2005) described as 'Pharmaceutical citizenship', where inaccessibility to pharmaceutical drugs like ART has been regarded as marginalisation or depriving the patients of a basic human right to biomedical treatment. Ecks, therefore, posted that pharmaceutical citizenship is about restoring back to society those that are at the margin of society (disadvantaged and stigmatised people) by removing the marginality imposed by their inaccessibility to medicine. Providing free antiretroviral drugs to people living in HIV in Nigeria and other parts of Africa is a form of pharmaceutical citizenship, by restoring back to society those that are at the margin of society (disadvantaged and stigmatised people) by removing the marginality imposed by their inaccessibility to medicine. Attaining a healthy lifestyle is increasingly tied to having access to pharmaceuticals (Petryna & Kleinman 2006). Access to free antiretroviral drugs is a new form of citizenship (Robins & von Lieres 2004), as HIV-positive individuals are convinced by the free antiretroviral treatment offered by the Nigerian state to improve their health and be integrated into the mainstream as citizens. With this pharmaceuticalisation of public health vis-à-vis the introduction of the ART programme in Nigeria, ‘citizenship in the era of biomedicalisation is governed through both rights and responsibilities: the rights to biotechnologies, treatment and care’ (Young et al. 2019:3).

This appropriation of free ART by people living with HIV, as a form of citizenship right, was regarded as legitimate by the Nigerian state, based on their biological condition. This form of ‘biological citizenship’ (Petryna 2002; Rose & Nova 2005) that was conferred on people living with HIV in Nigeria is the means by which access to free antiretroviral medications becomes part of their legal right as citizens of the state. Biological citizenship (having HIV is the biological basis for claiming legal and social rights from the state), therefore, becomes the basis of pharmaceutical citizenship for people living with HIV in Nigeria to access free medications. As pharmaceutical citizens, access to free antiretroviral medications is therefore central to the way in which HIV-positive people act upon their ‘diseased bodies’ and appropriate citizenship as part of contemporary expression of the legal-self in society.

Following the age of pharmaceuticalisation of public health, the free ART programme in Nigeria that facilitated pharmaceutical citizenship was reinforced by the therapeutic citizenship advocated by Nguyen (2005; 2007; 2011). In fact, to deepen this argument requires a brief analysis into the historical background of therapeutic citizenship. The concept of therapeutic citizenship was articulated based on the experience of HIV treatment access in West Africa in the 1990s, when Vinh-Kim Nguyen conducted ethnographical studies on the role of international aids/donor organisations and non-governmental organisations (NGOs) in facilitating treatment access to people living with HIV in resource-scarce (and treatment-scarce) settings in Burkina Faso, Côte d'Ivoire, and Mali. Due to political instability and lack of capacity/capability of the state health systems to cope with and respond to medical problems occasioned by the ravaging AIDS crisis, amidst the lack of treatment provision for people living with HIV in these three African countries, Nguyen (2011) noted that international aids/donor organisations stepped in and developed 'sovereignty over who could live or die' (Czapp 2012: 357).

As these international aid/donor organisations provided life-saving HIV drugs, albeit in limited capacity, the question of who deserved to have access to HIV treatment provided by these organisations was the key issue. HIV patients recruited for treatment by these organisations are expected to 'engage in processes of self-improvement to present themselves as worthy candidates for treatment' (Rhodes et al. 2013: 1024). As Mfecane (2011: 130) noted, recruited HIV patients are expected to play 'active roles in taking good care of their health and adjusting their lifestyles in accordance with behavioural prescriptions set by the NGOs providing care and support for them', by performing certain obligations and responsibilities to be eligible for continuous treatment. These obligations and responsibilities include asserting their rights as a collective based on their HIV condition, making claims for treatment, and behaving as 'responsible' patients by adhering to the treatment regimen. Those who have succeeded in the performance of their obligations and responsibilities 'are triaged into ART as potentially valuable members of an emerging HIV/AIDS community' (Paparini & Rhodes 2016: 504). These international aids/donor organisations 'exert power through the resources they offered (HIV drugs) and imposed some conditionalities to those assessing the treatment, with a view to fashioning particular kinds of subjects (HIV patients)' (Nguyen 2005).

The assemblage of these HIV/AIDS-funding and support group organisations in Africa, as Nguyen observed, has resulted in the formation of new support networks for people living with HIV. Therapeutic citizenship is, therefore, about a political claim to belonging to a global community that offers access to treatment, by relying on illness condition to negotiate complex issues such as survival, social relationship, access to resources, and rights and responsibilities around personal engagement and self-management of HIV (Nguyen et al. 2007; Nguyen 2011; Russell et al. 2016; Zhou 2019). An active treatment engagement undertaken by people living with HIV, as Rhodes et al. (2013: 1024) noted, ‘makes citizenship through enabling claims to a variety of medical, material, and other resources’ and undertake collective actions based on their shared illness identities.

The application of therapeutic citizenship has been deployed to explain HIV treatment access in other African settings, especially Gambia (Cassidy & Leach 2009), Uganda (Russell et al. 2016), Malawi (Zhou 2019), South Africa (Robin 2005; 2009; Steinberg 2008; Mfecane 2011), Tanzania (Mattes 2011; Marsland 2012), Zambia (Patterson 2016; Mulubale et al. 2020; Mulubale 2020) and a non-African context like Brazil (Biehl 2007; Cataldo 2008), Serbia (Bernays et al. 2010), as scholars have empirically extended Nguyen’s approach to understand the distribution of life-saving antiretroviral medicines in different contexts. Even though these studies have supported and reaffirmed the claims of therapeutic citizenship, other scholars have critiqued the concept and argued that it does not reflect the experiences of people living with HIV in some African contexts. For instance, Robins (2009) observed that HIV-positive men in South Africa are not comfortable with an HIV identity and their membership in the support group does not lead to a complete break from the past behaviours and practices.

Cassidy & Leach (2009) and Colvin et al. (2010) argued that therapeutic citizenship is unrealistic in contexts where HIV-positive people were reluctant to participate in HIV/AIDS activism in their communities due to fear of stigmatisation that emanated from their HIV disclosure. Other criticisms of therapeutic citizenship in Africa argued that therapeutic citizenship created docile and passive HIV patients at ART clinics, where providers exert power to control patients (Mattes 2011). Finally, Mulubale et al. (2020) observed that the Zambian state, rather than aids/donor organisations or NGOs, is the provider of ART, with no role for the latter in HIV treatment services, but aids/donor organisations or NGOs were active in the provision of psychosocial resources for people living with HIV. The critique of therapeutic citizenship in the Nigerian context shares a striking similarity with the observation of Mulubale et al.

(2020) in Zambia. This is because, in 2005, when Nguyen articulated therapeutic citizenship, Nigeria had already started a free ART programme, and therefore most of the claims in therapeutic citizenship are not relevant as far as the Nigerian HIV situation is concerned.

Therapeutic citizenship is less relevant in contexts where the state (national government) provides free antiretroviral therapy to HIV patients and where there is no direct relationship between aids/donor organisations and HIV patients in terms of treatment access. In Nigeria, the relationship between HIV patients and aids/donor organisations to treatment access is not direct or does not exist. As in the Zambia case, the Nigerian state is the provider of ART, with no role for the aid/donor organisations or NGOs in HIV treatment services. However, aids/donor organisations or NGOs could provide psychosocial resources for people living with HIV. In contrast to Nguyen, the state could not be relied upon to secure treatment support necessary for survival in those West African states, but in the Nigerian setting the state provided free ART programmes and, therefore, could be relied upon to provide treatment support for HIV patients. Therefore, the claim of biological citizenship has been activated by people living with HIV, while pharmaceutical citizenship has already taken place in the Nigerian context when therapeutic citizenship was articulated.

Furthermore, the right to access free ART has been activated by biological citizenship of people living with HIV prior to the involvement of support groups. Support groups are formed in Nigeria in the respective treatment centres after people living with HIV have been enrolled into ART programmes. Therefore, HIV support groups only engage in activism by campaigning for continual sustainability of the current ART programmes.

Despite these criticisms, one area where therapeutic citizenship is applicable to Nigeria is where the provider of free ART (Nigerian state administered through state and private healthcare institutions) emphasises not only adherence to ART, but that testing, counselling and support group participation are part of the responsibilities of the HIV patients. This is part of the conditions for enrolment of HIV patients into free ART programmes. As far as Nigeria’s HIV/AIDS situation is concerned, therapeutic citizenship helps to foster a process of discipline on the part of HIV patients and commits them to the performance of their obligations—adherence, post-treatment testing, post-treatment counselling and support group participation as part of the conditionalities associated with the enrolment into ART programmes. In this regard, therapeutic citizenship within the context of free ART programmes in Nigeria helps in making HIV technologies work effectively and constitutes ‘a site for the exercise of disciplinary requirements on citizens’ (Davis & Squire 2010: 195) and affords people living with HIV to claim the right to health and socio-political inclusion following the activation of support group networks and new alliances with state health apparatus. In this sense, therapeutic citizenship only complements the existing relationship and assemblage fostered by pharmaceutical citizenship.

Therefore, the pharmaceuticalisation of public health, vis-à-vis the provision of free antiretroviral drugs in Nigeria, is inundated with a complex matrix where biological, pharmaceutical, and therapeutic citizenship is intertwined in the social and political claims and rights to treatment, as well as the daily experience of living with HIV. This pharmaceuticalisation of public health in Nigeria constituted a significant improvement in the age of intervention and was more important in the HIV policy history than the age of denial.

1.6 Social issues around HIV/AIDS in Nigeria

The reality and situation of HIV/AIDS in Nigeria cannot simply be reduced to biological facts (disease) and public health issues around HIV prevention and vaccination, which could be reduced to the activities of government officials and health workers. Rather, it was social issues that are drawn from the lived experience of living with HIV, government responses to HIV/AIDS, and the cultural understanding of HIV in Nigeria. These social issues, which include discrimination and stigmatisation, HIV and religion, are important discourses that underpinned the reality and understanding of HIV/AIDS in Nigeria. These issues are discussed in the subsections to follow.

1.6.1 Discrimination and Stigmatisation

At the beginning of the HIV/AIDS epidemic, those suspected of being infected with the virus were subjected to discrimination, marginalisation, and social ostracism (Herek & Glunt 1988; Gostin & Webber 1998; Zierler et al. 2000; Herek et al. 2003;

Kuriansky 2016). Being diagnosed with HIV in Africa, especially in Nigeria, carried the weight of discrimination and stigmatisation. This is because the cultural understanding of HIV was that there was no cure for it, and whoever was infected with HIV had been handed their death warrant. Therefore, people living with HIV were culturally regarded as morally perverted, adulterous, promiscuous or sex workers (Smith 2004). As a new terrifying disease, HIV possessed the ‘emergence of a disease whose charge of stigmatization and whose capacity to create spoiled identity was far greater’ (Sontag 1978:16). Because of this, in most sub-Saharan African societies, especially Nigeria, HIV was regarded as a viral enemy identified with evil and attached blame to its victims (ibid).

This negative stereotype associated with HIV in Nigeria might have constituted the basis for the discrimination and stigmatisation against people living with HIV. From 1986 to date in Nigeria, HIV-positive people are stigmatised and discriminated against, because their illness is seen as a contagious disease and the lack of a cure is a threat to the community. In a systematic review conducted by Bharat (2011), it was observed that half of the respondents, including the healthcare providers, had blamed people living with HIV/AIDS for bringing the disease into the community. Because of the threat posed by HIV incurability, HIV-positive people are shunned, rejected, and ostracised by family/relatives, friendship networks, peer groups, religious organisations and other sites of social groupings where they may experience harassment, threats of violence, public restrictions and sanctions (Letamo 2004).

Apart from Nigeria, studies from other sub-Saharan Africa countries have shown that people living with HIV are often stigmatised and discriminated against in social life (Miller & Rubin 2007; Greeff et al. 2008; Dahlui et al. 2015). The instances of discrimination and stigmatisation that have been reported in other African countries include name calling, pointing fingers at those infected with HIV, mocking abusive language to HIV patients, denial of training opportunities, promotion, career advancement, refusal of job placement, segregation in hospital wards, loss of job, threat or target of violence, and, in the most extreme cases, violent murders (Ehiri et al. 2005; Mutalemwa et al. 2008; Olley et al. 2016). Ogunrotifa (2020) observed that consequences of discrimination and stigmatisation to HIV-positive people, especially in Nigeria, is the loss of a membership of a social group in the community. This loss of social membership for HIV-positive people means loss of rights, status, duties, and belonging as a full member of a group (family, clubs), and thus prevented them from 'participating in the lives of their communities and limited their access to critical social and economic resources' (Izugbara & Wekesa 2011: 874). The implication of loss of social membership is the othering for people living with HIV. Othering (or otherness) in this regard means that people living with HIV are regarded as 'others' in the society and, therefore, it is believed that these individuals deserve to be stigmatised and discriminated against. With othering, people living with HIV could be categorised as pariahs and unwanted elements in society and, thus, are pushed to the margin of society. The effects of othering are the reflections of these consequences of stigmatisation and discrimination.

Due to discrimination and stigmatisation, HIV disclosure, avoidance of treatment and concealment of HIV status are major barriers to testing, treatment uptake, and adherence in Nigeria (Amoran 2012; Okareh et al. 2015; Odimegwu et al. 2017). Other studies have shown that discrimination and stigmatisation undermine HIV testing (Yahaya et al. 2010), retention and adherence to treatment (Okoronkwo et al. 2013; Rueda et al. 2016), inequalities in accessing HIV support, care, and treatment (Ehiri et al. 2016). However, several studies have identified a few health problems posed by discrimination and stigmatisation of people living with HIV and these includes isolation, depression, loneliness, low self-esteem, lack of interest towards practising HIV preventive measures, low health-seeking behaviour, and failure to participate in in routine HIV testing (Valdiserri 2002; Parker & Aggleton 2003; Nyblade & MacQuarrie 2006; Babalola 2007; Mokoae et al. 2008; Onyebuchi-Iwudibia & Brown 2014; Stangl et al. 2019).

Exclusion and marginalisation from the community are the consequences of discrimination and stigmatisation that are usually experienced by people living with HIV/AIDS. The social issues caused by discrimination and stigmatisation have been the realities faced and experienced by people living with HIV in Nigeria from 1986 to date. However, some changes that have taken place recently, such as free antiretroviral therapy in Nigeria since 2002, and the recent scientific transformation in HIV drug therapies, have transformed HIV not only into a manageable chronic illness, but also to an undetectable status. Yet, people living with HIV are still being defined within cultural parlance, and are still being discriminated against as having uncurable HIV, while undetectable people living with HIV are still regarded as having a HIV body (Young et al. 2019).

As previously stated, people living with HIV will not disclose their HIV-positive status to avoid being ostracised and isolated from participating in social life and cultural events, and therefore continue to engage in high-risk behaviour (Mokoae et al. 2008). From 2002, when ART was free to people living with HIV in Nigeria, available evidence suggests that ART has not reduced underlying structural drivers of discrimination and stigmatisation (Russell et al. 2016). Nevertheless, the increased uptake of ART in some developing countries in the last 10 years has resulted in the reduction of the stigmatising characteristics, as disease progression is reversed or halted, thereby changing the social experience of the disease (Castro & Farmer 2005). This is evident in recent studies by Castro and Farmer (2005), where it was found that ART helped to reduce felt and enacted stigma in Haiti, while a research in South Africa found that HIV-positive individuals openly disclosed their HIV status following their recovery through ART, which encouraged them to become activists in the campaigns for expanded treatment access (Robins 2006).

Even in recent years when therapeutic advancement in antiretroviral drugs has facilitated undetectability as untransmittable (U=U), people living with HIV in Nigeria have still been considered as ‘infectious others’ and, hence, they are still being subjected to discrimination and stigmatisation. A recent social media campaign was undertaken by a group of clinicians, community and HIV organisations and researchers in July 2016, under the auspices of Prevention Access Campaign to promote the narrative of ‘Undetectable = Untransmittable’ or ‘#U=U’ (Young et al. 2019; Prevention Access Campaign 2016). Despite the media attention and publicity that this social media campaign generated, especially in Western countries, the campaign was limited to the idea of reducing stigma and fear of transmission rather than addressing the risk issue associated with HIV undetectability. The impact of such a campaign in developing countries, especially sub-Saharan African countries, is unknown, but the cultural inscription of HIV as an incurable disease still lingers in the people’s imagination, and this continues to make discrimination and stigmatisation social issues that people living with HIV/AIDS in Nigeria face in their everyday lives. Therefore, the emotional impact of discrimination and stigmatisation contributes to the psychological, physical, and social burden of illness or HIV in everyday life.

1.6.2 HIV and Religion

The cultural understanding of HIV, which underpinned discrimination and stigmatisation, also found its expression in the religious dimension of response and reaction to HIV. The close alignment between cultural traditions and religious practices is more prevalent in Africa, as Africans sought religious and spiritual approaches as a way of understanding and responding to the suffering and mortality caused by HIV/AIDS (Tocco 2017). This is evident in Africa where the religious values, beliefs and practices of their leaders and followers of Christianity and Islam—the two dominant religions on the continent—shape their conception of disease and illness, such as HIV (Speakman 2012). HIV, then, was a life-threatening disease that was feared in the extreme. Religion, especially Christianity, further entrenched the cultural inscription of the HIV body as a product of spiritual pollution and immorality that manifested from promiscuous, adulterous, and sinful sexual practices (Palmer 1989; Togaresi 2010; Root 2009; Leusenkamp 2010; Aguwa 2010).

In the early years of the HIV epidemic in Africa, the reactions of these two religions contributed immensely to the spread of the epidemic, by deepening the stereotype, prejudices and stigmatisation associated with HIV, and thus undermining HIV prevention strategies. Given the different faith-based bodies and organisations around these two religions, there are different responses to HIV and AIDS. Despite these differences, both religions unwittingly ‘contributed to the spread of the virus by rejecting condom use and allowing the stigmatisation of people living with HIV or AIDS’ (Balogun 2010: 459). Even though both religions have different responses to HIV/AIDS, their moralistic stance on what is acceptable or unacceptable in interpreting social reality shapes their understanding about HIV/AIDS.

In comparing the impact of religious discourse on HIV/AIDS in Africa, Speakman (2012) argued that the conservative positions of Christian religious leaders had a profound effect on the social construction of the HIV/AIDS epidemic in Africa in five ways: what language is used to describe the disease; how people with the disease are morally judged; what social problems are associated with the disease; societal changes that are linked with the disease; and the ways in which discussions of the disease reveal certain biases. In the context of Christianity, HIV/AIDS is linked to practices such as extramarital affairs (adultery), homosexuality, bodily contamination sexual promiscuity, female sex workers and other practices that were believed to have incurred divine punishment from God (Genberg et al. 2009). In Christian religious discourse, HIV is associated with punishment from God, by indulging in sinful lifestyles, morally and religiously disapproved behaviours and practices, and thus blame is placed on men and women for transgressing the rules of the divine order (Smith 2007; Ucheaga & Hartwig 2010; Rhine 2015). In this regard, the burden of illness or HIV is usually placed on the shoulders of the victims, and considered as the responsibility of the affected individual, therefore exposing them to blame and judgement. This social construction of HIV often results in the creation of stigma due to people's uninformed epidemiological understandings about HIV/AIDS (Speakman 2012). Due to this fact, people living with HIV are not protected from the social stigma associated with the disease.

Throughout the 1980s and 1990s, this has been the response of the Christian faith and its leadership to HIV, and such responses have been demoralising to people living with HIV/AIDS. Churches and other religious organisations, as Palmer (1989: 50) concluded, 'condemn HIV victims and exclude them from their congregation' and thus placed the burden of guilt on the victims or patients. The social meaning of HIV/AIDS, as Conrad (1986) pointed out, hinges on how cultures define an illness as devastating and its consequences as moral shame for those who had the ill luck to be infected by it in the first place. Although churches provided psychological, spiritual, religious, and social support to their numerous members (Adogame 2007), the judgemental attitude towards people living with HIV fostered the spate of stigmatisation that HIV/AIDS sufferers faced within this period. As our knowledge about HIV has improved in the last two decades, the judgement and stigma placed on people living with HIV has changed, while the Church's response to HIV/AIDS has improved. However, the religious moral framework that underpinned the Church's understanding of diseases and illnesses still acts as the bulwark against HIV prevention strategies. This is because the conception of a disease like HIV as a penalty of God's punishment often results in the Church's passive attitudes towards campaigning or developing HIV prevention strategies.

The public and private responses to HIV by Christian religious leaders have had a profound impact on the care and treatment of their followers who are HIV-positive, by providing counselling and showing compassion and empathy for the suffering they experienced. However, their message on prevention is still problematic for two reasons. The first is that Christianity's teaching of abstinence from sexual intercourse and monogamy is considered as a challenge for HIV/AIDS-health communication and intervention (Smith 2004; 2014; Ochillo et al. 2017; Usadolo 2019). Since they believe that HIV is transmitted through sexual intercourse only, Christian religious leaders focus on a message of abstinence and fidelity through their sermons as a means of education and prevention and bracket off other means of HIV prevention to preserve the sanctity of the Christian faith. In this regard, the campaign around the condom as a form of contraception is eschewed because it is considered as immoral (Aguwa 2010), as condom use is regarded as an encouragement of sexual immorality, especially among youths.

Second, the Church's message and position on homosexuality, sexual promiscuity/infidelity, and prostitution prevented its religious leaders from adopting other effective HIV prevention strategies because they do not want to be perceived as endorsing stigmatised groups such as gay males or female sex workers (Adogame 2007). Therefore, the role of the Christian faith, especially churches in the current war against the HIV/AIDS epidemic, has not been effective.

Like Christianity, the Islamic response to HIV/AIDS in the early period of the epidemic has been dismal, slow, and negative. The differences between Christianity and Islam's beliefs and values had led to contrasting conceptions of the disease in Nigeria. Although both religions disagree on the conception of HIV, they both agree on the mode of HIV transmission and HIV prevention strategies. This can be seen in two ways. First, the Islamic religion holds that diseases such as HIV come from Allah (Al-Jibaly 2003) and, therefore, people living with HIV or other ailments should not be considered as sinners or to be stigmatised (Balogun 2010). Rather, people living with HIV should be considered as normal people that should be shown love, care and mercy (ibid). In essence, Islam does not attribute HIV to the sins of man, but rather holds that HIV epidemics are tests of faith from Allah (Al-Jibaly 2003). Due to this stance, Islam discourages the discrimination and stigmatisation of people with any kind of ailment, and do not believe that people living with HIV have been contaminated by sins and immoral practices. Second, whilst Christianity focused extensively on its tenet of monogamy as a bulwark against HIV/AIDS, Islam accepts that polygamy is an effective antidote to HIV/AIDS (Saddiq et al. 2010). Christians believed that the husband might not be able to sexually satisfy his wives in a polygamous marriage, and hence such wives will resort to seeking extramarital sexual satisfactions. Christian religious leaders thus believe that a polygamous marriage is responsible for promoting vulnerability to HIV in a familial setting (ibid). In contrast, Muslims believe that polygamy helps to curb men's extramarital sexual desires, as wives waiting for their sexual turn in a polygamous affair 'might not necessarily promote female promiscuity' (Ibid: 147). In a patriarchal gender context like Nigeria, polygamy might be advantageous to men (husbands) in fulfilling their sexual desires but might not be beneficial to the women (wives) who want an active and satisfactory sexual life. This could lead to women having extramarital affairs, the outcome of which could lead to a vulnerability to HIV in familial settings.

These contrasting positions of the two religions on the conception of a disease like HIV illustrate the important social issue that a religious moral framework fosters in the everyday management of HIV. Like Christianity, Muslim communities hold that HIV spreads through sexual promiscuity (Speakman 2012), and this contributes to the stigmatising of HIV/AIDS.

Secondly, Muslim and Christian communities oppose homosexuality in any form and believe that it contributes to the spread of HIV/AIDS (Speakman 2012). This is more reason why both religions supported the enactment of the harsh anti-gay law in Nigeria in 2014. Thirdly, Muslim communities oppose the national HIV/AIDS prevention initiatives, which emphasised the safer and protected sex using condoms. The Islamic religious leadership does not oppose the use of the condom between couples in a marital relationship, but does oppose its usage outside the marriage. In this sense, Islamic bodies in Nigeria oppose the secular campaign around the public promotion of the condom because it is believed that it encourages people to engage in immoral sexual promiscuity in the name of protected or safer-sex practices (Balogun 2010). Rather, strict adherence to Islamic teachings on faithful marital relationships, sexual faithfulness in marriage, and sexual abstinence outside of marriage are seen by most Muslims as solutions to the spread of HIV (ibid).

Finally, like Christianity, the Islamic religious leadership offers compassion and support to the care and treatment of people living with HIV, especially AIDS-orphaned children (Ucheaga & Hartwig 2010; Oluduro 2010; Ajuwa 2010; Olaore & Olaore 2014). In 2009, the Nigerian Supreme Council for Islamic Affairs (NSCIA)—the umbrella body of Muslim communities in Nigeria—published a national Islamic policy on HIV/AIDS. The policy, which was the Muslim response to HIV and AIDS in Nigeria, aligned with mainstream biomedical approaches to treating HIV and AIDS and emphasised strict adherence to the national treatment guidelines issued by NACA (Tocco 2010; 2017). Where the Islamic response on HIV treatment differs is the emphasis on the close connection between treatment and religious obligation during compulsory Ramadan fasting (Tocco 2017). Adherence to ART conflicts with the spiritual requirement of Ramadan fasting, as Islamic law and principles allow sick Muslims to refrain from fasting in the month of Ramadan, but to complete their missed fasting when they have recovered from the illness, often after Ramadan (Balogun 2010). Since effective HIV treatment requires adherence, inability to Ramadan fasting usually invites suspicion from members of the community/public. The dilemma between adherence to ART and observance of religious fasting is a social issue that people living with HIV/AIDS in Nigeria face in their religious life. Tocco (2017) observed that there is no consensus among Muslims living with HIV on how to resolve this issue, as many HIV patients adjust dosing guidelines to accommodate the spiritual obligations associated with fasting.

The role of religion as a response to HIV/AIDS in Nigeria has been instrumental to the way people living with HIV manage their conditions in daily life. This religious worldview strongly influences not only the conception of disease and understanding of illness, as people interpret HIV and make sense of the epidemic within a religious moral framework, but also the balance between adherence to HIV treatment and the observance of religious obligation, mainly fasting, that are fundamentally opposed. Despite the differences and similarities in the responses of Christian and Muslim communities to HIV/AIDS in Nigeria, the religious moral framework that coloured their responses to HIV/AIDS often results in creating stigma/stigmatisation for people living with HIV and undermines the national prevention strategies designed to stop the spread of the epidemic. This is one of the important social issues that has defined the HIV/AIDS situation in Nigeria.

Generally, this section has addressed the social issues that underpinned the understanding of HIV/AIDS in Nigeria. The plethora of discourses arising from HIV and the body, discrimination and stigmatisation to HIV and religion have demonstrated the significant issues that shaped the reality of living with HIV in everyday life in the Nigerian context. These social issues that shaped HIV/AIDS, together with Nigeria’s HIV epidemic history, constituted the understanding and reality of the HIV/AIDS situation in Nigeria.

1.7 The aim of the study

The aim of this study is to explore other practices that people living with HIV undertake around their health to support the treatment they receive, and which revolve around the notion of healthwork. The overall research question for this study is the following: What are the consequences of healthwork on the biographies of HIV-positive individuals? The biography here consists of biographical time, the body and self/identity that are implicit in daily experiences of HIV-positive persons (Corbin & Strauss 1987). By investigating biography and its components (biographical time, the body, and conception of self) as far as the management of HIV in everyday life is concerned, the study explored the following three questions: What impact does healthwork have on the biographical temporality of HIV-positive individuals? How is the corporeal sense of HIV infectiousness/non-infectiousness shaped by the healthwork of HIV-positive people in everyday life? What are the impacts of healthwork on self and identity of HIV-positive individuals? These questions, which emerged following the review of the literature (which is presented in Chapter Two), were addressed through a qualitative methodological approach. This involved conducting semi-structured interviews with 32 people (men and women) living with HIV, and who have been on ART for at least two years. These participants were recruited through two HIV support groups in South-Western Nigeria. The interviews were audio-taped and transcribed verbatim. The computer-assisted qualitative data analysis software (CAQDAS) Nvivo 12 was used to facilitate the coding and analysis of the data. A thematic method was used for the analysis of this research. Thematic approach is useful in unpacking the content and patterns in the data collected.

The findings of this study helped to further enhance sociological knowledge on HIV management. These findings have potential implications on how healthwork can be integrated into the biography and social fabric of ill persons in relation to the management of their illness condition. The findings may also have further implications for health service delivery. Further details about the findings and contributions of this research will be provided in Chapters Four to Seven, and a tentative outline of the structure of the thesis is presented in the next section.

1.8 Structure of the thesis

The next chapter, which is the literature review chapter (Chapter Two), provides an in-depth review of the existing research that explores two important sociological topics: HIV as a chronic illness and HIV management. Through the review of literature on HIV management, the chapter shows the limits of adherence and healthwork, and introduces the notion of biography, body, and the conception of self to account for the important aspect of healthwork that has been neglected. It then attempts to map out key areas of focus in this thesis, as well as the research questions.

Chapter Three is the methodology chapter, which describes the methodological approach that was employed in answering the research questions posed at the end of Chapter Two. The chapter began by providing an overview of theoretical orientations and set the context for the epistemological and ontological foundation for this research. The chapter further provided a justification for why a qualitative method and interview technique were chosen, and highlighted how ethical approval procedures, fieldwork procedures, sampling methods and methods of analysis were undertaken. Chapter Four is a substantive chapter that explores the lay understanding of healthwork undertaken by HIV-positive individuals in Nigeria. The findings in this chapter have significant implications in grounding and answering the research questions for this study that were presented in subsequent chapters in this project. Chapter Five explores the impact of healthwork on the biographical temporality of HIV-positive individuals. The chapter begins by exploring how HIV disrupted the biographical temporality of people living with HIV and how healthwork helps to reconstruct their disrupted biographical temporality. Chapter Six further explores the impacts of healthwork on corporeal construction of HIV non-infectiousness in everyday life and how HIV-positive people construct their corporealities of infectiousness and non-infectiousness following the onset of HIV, especially in the HAART era. In the final analytical chapter, which is Chapter Seven, the chapter explored how HIV-positive people construct their sense of self following a HIV diagnosis and the impact of healthwork on HIV-positive individuals' sense of self in everyday life. Chapter Eight, which is the last chapter of this thesis, discusses the key findings and the contributions of this research to sociological knowledge, the limitations of this study, the implications of this study's findings for further research, and the concluding remarks.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature on HIV management and articulates a sociological framework for this research project. To build a case regarding why the research questions posed in Chapter One are worth exploring, this chapter provides an in-depth review of existing research that explores three important sociological topics: HIV management in a pre-HAART era, HIV management in the HAART epoch, and healthwork. The era of HAART, which is a highly active antiretroviral therapy, represented an important phase in the history of HIV treatment across the world. Therefore, researching HIV management around HAART would help to provide a thematic structure to review the developments around HIV treatment in the last three decades.

Reviewing the literature around these topics is necessary for this research because of three reasons. The first is the negation of biographical issues in HIV management in the Nigerian context. The second is to situate the consequences of healthwork on everyday lives of HIV-positive persons within the interlocking themes associated with biography: biographical time, the body, and self/identity. The third is to identify the gaps in HIV management that create a pathway for enhancing sociological knowledge on HIV management, by using the findings of this research to understand how healthwork can be integrated into the personal and social fabric of ill persons as the core basis of illness management.

The chapter begins with the mapping of the sociological approach to HIV management in the early stage of its development before the highly active antiretroviral therapy (HAART) called pre-HAART in section 2.2 is discussed. The contour of HIV management changed significantly during the HAART era, which made for a better understanding of HIV management in the HAART era to be different from that of the pre-HAART epoch. Therefore, section 2.3 is devoted to reviewing literature on HIV management in HAART, fleshing out changes that occurred in that epoch. The third section, which is section 2.4, delves into the notion of healthwork as the important gap in the sociological understanding of HIV management. This section expands the concept of healthwork to accommodate biographical issues of biographical time, the body, and self/identity that have profound implications for the management of HIV as a chronic condition in the contemporary era.

2.2 HIV management in pre-HAART era

Prior to 1982, the notions of Acquired Immune Deficiency Syndrome (AIDS) and HIV did not exist in the vocabulary of medicine. The report of unidentified diseases among gay men and intravenous drug users in the United States triggered a wave of investigation which forged ‘a new diagnostic category, produced an explanatory mechanism, identified an infectious agent to which the origin of the disease was attributed, and led to the development of tests’ (Camargo 2013: 845). Following its categorisation as a disease, HIV was considered as a medical condition that required pharmaceutical intervention to prolong the life of affected individuals and to prevent it from developing into AIDS. This categorisation led to the development of drugs that are crucial towards slowing down the reproduction rate of the virus in the body and preventing it from developing into full-blown AIDS. As a result, the first antiretroviral drug—Zidovudine (AZT)—was developed in 1987 (Brook 1987). AZT is a nucleoside reverse transcriptase *inhibitor (NNRTIs),* a drug that was developed for the treatment of HIV (Vella et al. 2012). The clinical trials concerning AZT treatment were associated with a greater survival at 24 weeks (Fischl et al. 1987), but by 48 weeks the survival benefits with AZT treatment were found to be limited (Fischl et al. 1993; Volberding et al. 1990). Therefore, AZT can only improve and prolong the survival rate of people living with HIV for a predetermined period of time. Despite its limitations and side effects, AZT was approved in 1987 for medical treatment of HIV. Between 1987 and 1991, AZT was widely marketed all over the world as the only prescribed antiretroviral drug capable of treating HIV and thus heralded the epoch of monotherapy in the HIV treatment regimen.

Despite the successes of AZT in controlling the virus, especially its breakthrough in the prevention of mother-to-child transmission (Connor et al. 1994), there exists uncertainty in relation to the problems posed by poor health and adverse side effects. The persistent problem of a low quality of life associated with these drugs undermined public confidence about its efficacies (Broder 2010). In fact, the publication of the controversial Concorde trial results, which revealed sudden and mass death of HIV-positive individuals treated with AZT compared to those who are simply affected by illnesses said to be AIDS-related in 1993 (Concorde Coordinating Committee 1994), called into question the efficacy of the monotherapy drug in combating HIV. Other studies revealed that AZT was characterised by health risks, susceptibility to viral resistance, and a low survival benefit for people living with HIV/AIDS (Volberding et al. 1990; Fischl et al. 1993) despite the effective adherence to the drug.

Because of the health problems attributed to AZT, there was a frantic search to develop other drugs that could be combined with it to tackle the shortcomings associated with the use of a single drug in the treatment of HIV. Because of this, another class of *NNRTIs* such as Didanosine, Zalcitabine, and Stavudine, were developed. When AZT was administered with Didanosine (ddC) or Stavudine in clinical trials, the treatment impact was significant, as the survival rate was found to have increased and performed better when two or more drugs were combined (Vella et al. 2012). Despite the therapeutic benefit of combining AZT with any of the other *NNRTIs* over a single therapy like AZT, the clinical benefit was still not durable (Hammer et al. 1996). Yet, Didanosine and other *NNRTIs* were approved for HIV treatment.

The approval of Didanosine, Zalcitabine, and Stavudine in 1992 and 1993 by the US Food and Drug Administration (FDA) came as a reprieve to most patients who wanted to change their therapy from AZT. However, viral resistance to these new *NRTIs* drugs is frequent but can be effectively suppressed if used in combination with AZT (Carpenter et al.1996). The combination of two nucleoside drugs in the treatment regimen of HIV suggests that a single (monotherapy) drug cannot adequately suppress viral resistance in the body cell. Therefore, the combination of AZT and other antiretroviral drugs are needed to stem the unhealthy tide of the therapeutic situation (Carpenter et al.1996). Further studies later confirmed that combining AZT with any of the *NNRTIs* class of drugs helps to dramatically inhibit viral replication and resistance, and the rebuilding of the weakened immune system (Saravolatz et al. 1996; Hammer et al. 1996). The historical development of antiretroviral therapy from 1987 to 1996 constituted the era of pre-HAART in HIV management.

The understanding of HIV management in the pre-HAART era within sociological discourse can be broadly contextualised under the general frame of the sociology of chronic illness. The sociological approach to the study of chronic illness was first articulated by Anselm Strauss and Barney Glaser following the publication of *Chronic Illness and Quality of Life* in 1975. Strauss and Glaser's publication emerged as part of the critiques of Talcott Parsons' (1951) notion of a sick role that emphasises patients' passivity in a clinical/medical encounter, or what Parsons regarded as the 'doctor-patient relationship'. Parsons' sick role model demonstrated how individuals' health contributes to their participation in social life in terms of roles and expectations and shapes the overall functioning of the social institutions in society. Parsons' theory had drawn the sociologists' attention to the problem of health/illness and fuelled sociological questioning of biomedicine in general. It was during the 1960s and 1970s that several sociologists, especially those from the Chicago School, sought to clarify and broaden Parsons' (1951) conception of the sick role and doctor-patient relationship by deconstructing patients' passivity in its application to chronic illness (see Berkanovic 1972; Gerson 1976; Gallagher 1976; Gerhardt 1979a).

Strauss and Glaser's work sought to reinforce the sociological critique of patients' passivity by demonstrating how chronically ill patients are actively involved in the management of their illness in everyday life. Through the notion of illness trajectory, Strauss and Glaser's (1965; 1968) path-breaking study explored patients' experience of chronic illness and, thus, ushered in pioneering research in the sociology of chronic illness[7] and that of the study of the illness experience. Following the pioneering efforts of Strauss and Glaser, sociological research into the consequences of chronic illness and the steps to mitigate its effects has proliferated as scholars have thoroughly applied the sociological approach to the understanding of a wide variety of chronic illnesses such as diabetes, asthma, heart disease, sickle-cell disease, cancer, stroke, etc., that have the potential to radically alter the everyday lives of ill persons. This has far-reaching impacts upon every aspect of their lives, especially employment, socio-economic status, romantic involvement, mortality and health, and permanent disability (Bury 1982; Schneider & Conrad

---

[7] Chronic illnesses refer to long-term conditions and disorders that exceed more than three months and cannot be cured or prevented by medications (WHO 2005) and 'interfere with social interaction and role performance' (Gabe et al. 2004: 77).

1983; Charmaz 1983;1987; 1991; 1994; 1995; 2000; Corbin & Strauss 1987; Bury & Anderson 1988; Bury 1991; Kelly 1992; Ciambrone 2000; Frank 2002; Lubkin & Larsen 2013).

However, another chronic condition that can have potential consequences for the everyday lives of the infected individuals is HIV. When HIV/AIDS emerged in the early 1980s, it was regarded as an acute condition which ‘causes fear of contagion among those who are healthy’ (Sandstrom 1990: 271). HIV/AIDS, however, generated public health concerns, a negative stereotype, and intense ‘public reactions to persons presumed to be infected by HIV’ (Herek & Glunt 1988: 887) in some Western countries, especially the United States. The liberal toleration of the gay community, which was limited at the time, became an uncertainty as the epidemic ‘generated new fears and heightened old hostilities’ (Brandt 1988: 367). Public understanding of the epidemic at the time was conceived as ‘the gay plague’, ‘the intravenous drug user syndrome’, and as a disease emanating from behaviours that were traditionally regarded as deviant (Herek & Glunt 1988).

The public response and social movement that followed the reactions to the outbreak of AIDS stimulated sociologists and social scientists to articulate a new perspective towards understanding the problems posed by HIV/AIDS. A substantial number of early social scientific studies focused on the social meaning of HIV as an illness (Conrad 1986; Palmer 1989; Sontag 1989). Nevertheless, sociological research on HIV/AIDS in the 1980s coalesced around the framework of traditional medical sociology, where the illness experience is prioritised rather than the specific biological and physiological symptoms. But the challenges remain whether HIV as an illness can be categorised as a potential chronic illness that has been studied in medical sociology (Pierret 1992: 71). This stems from the fact that, within five years of its emergence as a global disease, HIV/AIDS diagnosis was seen as a terminal illness, and became a leading cause of death in the relatively short term for young people aged between 25 and 44 years (Cox 2002), as there was no known medical treatment. This, however, compelled sociologists and other social scientists to question whether HIV/AIDS is a chronic illness, and whether existing concepts in sociology of health and illness were sufficient in understanding the impact of this new illness on the everyday lives of those infected (Pierret 2000).

The development of the first antiretroviral drug, Zidovudine (AZT), in 1987 made HIV a manageable chronic illness for a much longer time, similar to hypertension, diabetes and cardiovascular conditions in a biological sense, even though the social context and experience would have been different. The subsequent declaration by Samuel Broder (principal scientist who developed AZT) at the international AIDS meeting in Montreal in June 1989, that HIV/AIDS was a chronic illness and its treatment regimen should follow the model of other chronic illnesses, laid the controversy to rest (Fee & Fox 1992). Such a public statement marked a paradigmatic shift in the social definition of AIDS from a terminal to a chronic illness (Scandlyn 2000).

Siegel and Krauss (1991) and Nokes (1991) argued that HIV-positive persons would live with their condition for more than a decade and struggle with the illness in everyday life, reinforcing the growing consideration that HIV/AIDS should be typically considered and analysed as a chronic illness within sociology. However, the development of protease inhibitor drugs that triggered triple drug combination therapy, also known as highly active antiretroviral therapy (HAART) in 1996, later affirmed the argument that HIV is a chronic illness (Siegel & Lekas 2002). By situating HIV within the framework of the sociology of chronic illness, early sociological research focused extensively on the consequences and impact of HIV (as a chronic illness) on the lives and identities of the sufferers who have to manage, day in day out, their illness situation in an everyday context (Pierret 2000). Such consequences of HIV involve the intersections of self and identities of HIV-positive persons in the everyday management of the illness away from hospice and healthcare centres, and the strategies used to cope with the condition. A sociological approach suggests that chronic illness raises the question of time rather than being ‘cured’ and concluded that the privileging of treatment as the effective way of relieving pains and symptoms and slowing debilitation in biomedicine marginalises other narratives of ways of managing this chronic condition. The treatment of HIV vis-à-vis antiretroviral therapy has made the illness more manageable as growing numbers of people are surviving; there is now a substantial reduction in the risk of HIV transmission and AIDS-related deaths, as HIV-positive people are living longer (Deek et al. 2013).

Analysing HIV within the framework of the sociology of chronic illness has produced a substantive number of studies that revolve around significant numbers of interesting themes such as adaptation and uncertainty, coping mechanisms, time, the impact of treatment, self, identity, and stigmatisation. For instance, one of the pioneering studies that set the pace for a formal inquiry into the lived experience of HIV management is Weitz’s (1989) study on how uncertainty affects people living with HIV/AIDS (PLWHA), and how they cope with that uncertainty. Weitz observed that uncertainty affects PLWHA at many different levels. Uncertainty ranges from when people realise they are at risk, once they start to have symptoms, to once they are diagnosed, and thus gives them the opportunity to question why they got infected, how to manage the condition in everyday activities, and how to live and die with the illness with dignity.

The study concludes that uncertainty has a greater impact on persons living with HIV than those who suffer from most other illnesses. The notion of uncertainty in Weltz’s study illustrates that people living with HIV are more likely than sufferers of other chronic illnesses to feel guilty about the behaviours that led to them becoming ill and face greater uncertainty than other ill persons in predicting how their illness will affect their lives.

Following uncertainty, another characteristic of chronic illness that was explored was coping. Pierret (1992) raised the question of how individuals cope with being HIV-positive in relation to how they interact with significant others, friends, work colleagues and healthcare professionals. Between 1989 and 1992, when Weitz and Pierret wrote about uncertainty and coping, respectively, the terrain of HIV management had changed following the development and approval of two additional HIV drugs, Stavudine (d4T) and Zalcitabine (ddC) (Martin et al. 2009), which have helped to reduce the uncertainty that people living with HIV have about mortality. With these new drugs, people living with HIV are more concerned about coping with their condition in everyday life, and such coping with HIV as Pierret (1992) observed involves the management of secrecy and stigmatisation and the ability of people living with HIV to confront images and stereotypes that arose out of being HIV-positive. The salience of Pierret’s work demonstrated how HIV-positive persons draw up coping mechanisms to reorganise their everyday life and manage their HIV condition following their diagnosis and interpretations of their new condition.

However, Pierret’s discussion on coping was similar to Weitz’s (1989) discussion on stigma management. What seems different in both studies was that those participants in Weitz’s study had developed non-stigmatising theories to explain illness causation and resorted to a bravado method to convince others that all is well with them as functioning human beings. Even though the terrain of HIV management hinged on monotherapy—the use of Zidovudine (AZT)—at the time of Weitz's research, the participants had learnt who and when to reveal their HIV positivity and how to educate others about HIV/AIDS much earlier than when Pierret's research was undertaken.

Nevertheless, the discussion of stigma management provided insight into how coping with the problem of stigmatisation constitutes an important problem faced by HIV-positive individuals in everyday life. Alonzo and Reynolds (1995) expanded the discussion on stigma management by articulating the notion of stigma trajectories to unpack the dilemma of stigma that people living with HIV faced and experienced, and how these experiences are affected by changes in the biophysical dimensions of HIV/AIDS. Drawing from the notion of trajectories developed by Corbin and Strauss (1987; 1988), Alonzo and Reynolds articulated four phases of HIV stigma trajectories, namely *at risk*, *diagnosis, latent* and *manifest* phases in which people living with HIV experience stigmatisation. Those at risk are those in a period of uncertainty in the stigma trajectory, who fear that their behaviours or contacts with those at risk have placed them at risk of being infected with HIV. Those at the diagnosis stage are the individuals whose responses to a HIV diagnosis are characterised by anger, disruptive anxiety, and are affected individuals who struggle with the consequences and meaning of a HIV status in terms of disclosure to companions, friends, family, and relevant others. Those at the latent stage are those who are covertly quite disruptive in terms of internal feelings of anxiety and stress experienced, even when the disease (HIV) is asymptomatic. At the manifest stage, individuals begin to experience stigmatisation following the physical manifestation of HIV symptoms such as sustained weight loss, oral/candidiasis (thrush), fatigue, and others.

These phases enable individuals living with HIV to cope with HIV-related stigma and the unpredictable experience of HIV trajectories by closely monitoring the illness course, symptoms, treatments, side effects, test results for infections, and other dimensions of the illness. By folding stigma trajectories into a wider frame of stigma management, Alonzo and Reynolds provided insight into the ideologies and networks that are utilised to adapt and construct an HIV identity, with a view to avoiding or minimising HIV-related stigma.

In extending Alonzo and Reynolds' stigma trajectories into the domain of Pierret's (1992) coping mechanism, the work of Siegel et al. (1998) on the problem of coping with stigma mapped out the varieties of stigma management strategies used in everyday management of HIV. Siegel and his colleagues expanded Alonzo and Reynolds' work on HIV stigma management strategies to accommodate the sense of self and social status. The categorisation of HIV stigma management strategies into reactive, intermediate, and proactive strategies enabled people living with HIV to challenge societal reactions to their illness. For instance, the participants who used the reactive strategy, concealed and controlled information about HIV/AIDS within their social network, creating distinctions between themselves and 'other', to avoid being discredited by hiding their HIV seropositive status, and by disclosing that they were selectively under 'safe' conditions. Those who utilised the intermediate strategy engaged in a gradual disclosure by raising the topic of AIDS in a general way, with a view to assessing other people's attitudes and their knowledge about HIV/AIDS. This would enable them to know how to further release information in future engagements.

Proactive strategies were used by people living with HIV to engage in a pre-emptive disclosure to present a positive framing of the illness to those in their close network and ignore or replace the negative images found in the popular discourse of AIDS. The purpose of the proactive strategy is to promote alternative perspectives about AIDS that undermine societal stigma. Siegel and his colleagues concluded that stigma management strategies are a pragmatic way in which people living with HIV manage the consequences of HIV-related stigma with a view to preserving their social status, maintaining a positive sense of self, and living a full and meaningful life.

In investigating the consequences of HIV management in everyday life, Carricaburu and Pierret (1995) focused on the meaning given to being HIV-positive and the reconstruction of their identities following diagnosis. Carricaburu and Pierret observed that being HIV-positive after diagnosis was a phase in the lives of HIV-positive men, during which they could reorganise their biographies and construct the necessary hope to go on fighting the illness. The construction of hope was observed to be part of cognitive, material, physical and relational resources that HIV-positive men mobilised to reorganise their everyday life and to reinforce the resilience to cope with uncertain future outcomes associated with bodily and physical health and well-being in the face of impending risk. The discussion of hope management in Carricaburu and Pierret's work demonstrated that the management of HIV infection in everyday life is intricately bound up with the social meanings and interpretations of the illness condition. These meanings and interpretations manifest in maintaining secrecy to live a normal life and reorient oneself (and identity) and mobilise resources to manage their conditions in everyday life.

Further research on the management of consequences of HIV in the pre-HAART era was Pierret's (2000) synthesis of studies on HIV. Pierret (2000) summarised the findings of HIV studies in the sociology of chronic illness around the notions of coping mechanisms, uncertainty, stigma management, secrecy and disclosure management, and adjustment strategies that have been discussed earlier. Pierret (2000) therefore concluded that these HIV management strategies were undertaken prior to the advent of HAART (highly active antiretroviral therapy) and may have lost their currency in the post-HAART period.

Pierret's observation, however, embodied an important critique that characterised early sociological studies on HIV: they are mostly interested or focused on the consequences of HIV diagnosis on the everyday lives of those infected, rather than examining the consequences of post-diagnostic health practices on the everyday lives of HIV-positive individuals. Also, most of the previous studies are focused on gay men, while other populations are scantily considered.

This is the critical point at which this research will take departure from previous works and offer a new direction and avenue for investigation. In this sense, I argue that HIV management in the HAART era is fundamentally different from that of the pre-HAART period, and it is important to examine and review other ways or approaches (away from early sociological notions) that can capture this new therapeutic development. Since the reduction in the amount of HIV in the body and the management of not spreading the virus by the infected individuals through effective use of different classes of antiretroviral therapy are central to HAART, the section to follow will consider HIV management in the HAART era.

2.3 HAART: the new onset of HIV management

The management of HIV in the HAART era is intricately connected to the development of new classes of antiretroviral drugs that made HIV to be more manageable than the pre-HAART epoch. Before reviewing the sociological issues of adherence and healthwork that underpinned HIV management in the HAART era, it is important to flesh out the clinical overview and historical context that heralded the onset of HAART.

The combination of AZT with other classes of NRTIs drugs in the treatment regimen of HIV patients marked the beginning of a therapeutic shift from monotherapy to a combination of therapies. However, an important watershed in the history of HAART was the paradigmatic shift of drug research and development away from dideoxynucleoside reverse transcriptase inhibitors (NRTIs) to non-dideoxynucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors in 1995 and 1996, respectively. NNRTIs and protease inhibitors are new classes of drugs that were developed to be effective in suppressing viruses that had been found to be resistant to NRTIs (Wynn et al. 2004). The efficacies of NNRTIs and protease inhibitor drugs demonstrate that dual therapy from different classes was more effective than dual therapy from the same class. The first kind of NNRTIs to be approved and licensed was Nevirapine in 1995, while Saquinavir was the first protease inhibitor that was developed and approved in 1996.

Because of the likelihood and risk of viral resistance, NNRTIs and protease inhibitors were approved only in combination therapy. This means that both drugs must be taken together to prevent the risk of viral resistance. Recent studies have shown that HIV suppression can be significantly achieved if Nevirapine is combined with either protease inhibitor drugs or AZT than being used as monotherapy (Podzamczer et al. 2002; van Leeuwen et al. 2003). The development of NNRTIs and protease inhibitors heralded the beginning of HAART, where three or more drugs from different classes (NRTIs, NNRTI and protease inhibitors) were combined to prevent the onset of symptoms or progression to AIDS and prolong the survival in HIV-positive people. The HAART regimen usually combines three or more different drugs such as two NRTIs and a protease inhibitor (PI), two NRTIs and a NNRTI or other such combinations (Delaney 2006; Palmisano & Vella 2011; Vella 2012). The combination of these regimens has proven to reduce the amount of the active virus and, in some cases, can lower the number of the active virus until it is undetectable by current blood-testing techniques (Wensing et al. 2010). This development witnessed rapid and significant improvement in the quality of life and life expectancy of HIV patients, and later accelerated the therapeutic landscape of HIV as a chronic illness. The efficacy of HAART treatment has been regarded as the ‘Lazarus syndrome’ where there are revival experiences of persons who once were reconciled to their deathbed from HIV/AIDS (Brashers et al. 1999). With the Lazarus syndrome, people living with HIV have witnessed renewed health and continued life following the use of the HAART treatment regimen, having previously been faced with certain death from AIDS. Such dramatic health renewal allowed HIV-positive individuals to renegotiate their new roles and concerns in relation to their career, identity, finances, and social relationships (Brashers et al. 1999: 202).

As far as HIV is concerned, the HAART regime plays an important role in the management of the HIV condition. This is because antiretroviral therapy may not cure the illness, but it is crucial in managing the condition in a stable way by altering the progression of the virus from developing into full-blown AIDS and preventing other opportunistic infections. Unlike monotherapy, the significant improvement in the quality of life and life expectancy of HIV patients embedded in HAART raised new questions and concerns about how the management of HIV in everyday life can be analysed (Pierret 2000). This is because the uncertainty associated with the monotherapy era necessitated HIV-positive individuals to construct hope for themselves and is unconnected or less relevant in the HAART era. However, the onset of HAART has not eradicated discrimination, hostility and prejudice related to the stigmatisation of HIV but has only minimised it, as people living with HIV are living longer in the HAART era unlike in the pre-HAART era, where AIDS-related deaths were rife. A few sociological studies have demonstrated that stigma management in the HAART era is similar to stigma management strategies in the pre-HAART era (Parker & Aggleton 2003; Cree et al. 2004; Nyblade 2006; LeBel 2008; Steward et al. 2011; Lekas et al. 2011; Nambiar 2012; Overstreet et al. 2013).

These studies reported that the experiences of HIV-related discrimination such as enacted stigma (Scrambler 2009) were less frequent, but the perceptions of felt stigma (Scrambler 2009) motivated people living with HIV to present themselves as normal, avoid disclosing their HIV status, restricting whom they tell, and where and what they disclose. The impact of HAART on stigma has reduced and minimised, as the recent HIV campaign around the Prevention Access Campaign demonstrated. In July 2016, a group of clinicians, community and HIV organisations and researchers, under the auspices of the Prevention Access Campaign, started a social media campaign tagged ‘Undetectable = Untransmittable’ or ‘#U=U’ (Young et al. 2019; Prevention Access Campaign 2016). Unlike in the pre-HAART era, where secrecy around HIV positivity was rife due to stigmatisation, the social media campaign of the Prevention Access Campaign has demonstrated that people living with HIV are more incentivised to disclose their HIV status now due to the effectiveness of HAART to foster undetectability and ‘untransmittability’. The media attention and publicity that this social media campaign generated has been significant in reducing the stigma and fear of transmission (Young et al. 2016).

Nevertheless, HAART now fosters a new mode of managing HIV when compared with the era of monotherapy. Unlike in the pre-HAART era, where HIV management is preoccupied with issues of stigma management, coping mechanisms, secrecy and disclosure management strategies, the significant issue of HIV management in the HAART era is adherence. In biomedical and social science studies on HIV, adherence has been identified as the basis of HIV management in the HAART era. Therefore, this study will now review the studies on adherence in the following section.

2.3.1 Adherence in HIV management

The terrain of adherence in HIV management has changed since 1996 when HAART was introduced. This is because, at the onset of the HAART regime, patients needed to take three or more highly potent pills, and adhere to complex timing and diets with a view to achieving viral suppression that culminated in slowing the progression to AIDS (Haug et al. 2006). However, newer medications are now co-formulated in a single tablet that is taken once a day and which has become safer and easier to take and adhere to (Margolis et al. 2017; Castillo-Mancilla & Haberer 2018). Despite these therapeutic changes in antiretroviral therapy development, understanding the nature of adherence in HIV management would be incomplete without deepening our understanding on how adherence was understood and utilised at the early stage of the HAART regime.

At the early stage of the HAART regime, HAART was a complex drug regimen that constituted an important problem for medication adherence because the complexity of the regime made it more difficult to adhere to, as the pill regimen was disruptive to the daily routine of users who resented taking pills daily and possibly throughout the rest of their lifetime (Chesney 2000). Then, taking antiretroviral medications regularly was often advocated for HIV suppression in biomedical literature (Weidle et al. 1998; Hecht et al. 1998; Nieuwkerk et al. 1998; Chesney 2003). In this sense, the biomedical model of HIV management revolves around a complex set of adherence practices to medication-taking. By adherence, I mean the extent to which a patient's behaviour (in terms of taking medications, following diets, or executing lifestyle changes) matches agreed recommendations from the prescriber (Horne et al. 2002; Leong et al. 2004; Lutfey 2005).

This preoccupation of biomedical researchers with adherence started in the era of monotherapy. There were concerns that AIDS-related death among young people between the ages of 25 and 40 years was caused by therapeutic ineffectiveness associated with a patient's behaviour in terms of non-adherence to AZT and other monotherapy drugs in the early 1990s (Cox 2002). When the new classes of antiretroviral drugs (protease inhibitor drugs) were developed (and thus heralded the beginning of the HAART era), adherence was emphasised in biomedical literature as the only way of managing the HIV condition (Vanhove et al. 1996; Hecht et al. 1998; Montaner et al. 1998; Bangsberg et al. 2000).

However, what biomedical researchers found problematic about adherence as the fulcrum of HIV management what that it revolves around how the concept should be assessed and enforced. Therefore, the measurement of adherence presents a clear methodological challenge, as there were difficulties in assessing and operationalising it. Despite the development of an adherence measurement such as patient’s self-reports, viral load, assays of drug levels in the blood, electronic monitoring system, pill counts, and refill history (Weidle et al. 1998; Hecht et al. 1998; Nieuwkerk et al.

1998; Chesney 2003), there seems to be no way out of the pervasive problem posed by measuring adherence. This is because patients exercise their agency by modifying their treatments, testing its (drug) efficacy by non-adherence, and restricting their dependence on drugs as part of the interpretations of their health conditions (Hunt et al. 1989; Chesney 2003).

To resolve the epistemological lacuna associated with adherence, biomedical researchers turned to behavioural and social scientists for assistance (Chesney et al. 2000:1600). A review of research on adherence in medical sociology revealed that no new insights have arisen from quantitative studies as theory, models and predictors of patients' behaviour have produced contradictory results (Vermeire et al. 2001). The problem of adherence remains pervasive and complex as numerous studies encounter difficulties in identifying its causes, and in defining and measuring adherence, which undermines efforts to evaluate methods for its enhancement.

Due to its inability to focus on lived experiences, the quantitative social researchers failed to address the problem of adherence, and thus led to the search for the social basis and contexts that are involved in behaviour towards adherence. The shift of engagement towards a qualitative approach produced a significant proportion of studies on lived experiences of adherence with different epistemological and methodological orientations. For instance, Mykhalovskiy et al. (2004) explored adherence as the basis of understanding everyday management of HIV and argued that sociological critiques of adherence ignore 'the multiple forms of power – biomedical authority, population-based forms of risk governance, and liberal techniques of the self' (Mykhalovskiy et al. 2004: 317) that underpinned the practice of adherence in an HIV context. By defending the biomedical stance, Mykhalovskiy and his colleagues concluded that adherence is the common interpretive frame through which people living with HIV expressed their relationships with their treatment.

The interest of biomedicine in qualitative methodology was to uncover the lived experience that underpins the barriers and facilitators of patients' non-adherence, that might be further tested through a quantitative approach (which is the epistemological orientation of biomedicine) to predict non-adherence. Therefore, by using qualitative methodology, sociological studies produced new insights in the meaning of adherence. Such work that contributed to this domain is McCoy's (2008) study of how adherence is exercised vis-à-vis the lived actualities of people taking HAART and the everyday work of adherence with respect to managing a daily medication schedule and dosage, timing framework for pill-taking, and the emotional response of medication use. Following interviews with people living with HIV in Toronto, Canada, McCoy considered that adherence to HAART involves a stricter commitment to time and self-work that is oriented towards managing the tension and alignment between self-will and mental readiness/conscious attention to stipulated clock time, pill schedule, and the physical availability of the pills.

McCoy's research underscored the reinforcement of the ideology of paternalism that underpinned adherence in biomedical literature. Based on paternalism, adherence (also known as compliance) was considered as part of the biomedical strategies to reinforce medical control over patients (Stimson 1974; Zola 1981; Trostle et al. 1983; Conrad 1985; Hunt et al. 1989; Donovan & Blake 1992). The biomedical ideology of adherence/compliance conceives patients as passive, disobedient, uncooperative, being a defaulter, and an unquestioning recipient of medical instruction. Despite this shortcoming associated with the study, McCoy's work directed attention to the actions that HIV-positive individuals take and how they practise adherence in the face of their condition.

The ideology of paternalism inherent in biomedical research on adherence has been resisted by a few sociological studies on HIV management that sought to break away from such an ideology. Scholars in this tradition sought to examine the personal experience of treatment and ill-health other than merely following doctors' recommendations. A notable study in this regard is Stevens and Hildebrandt's (2009) study on what it means when an HIV-infected woman persistently does something other than what the doctor recommends her to do. Stevens and Hildebrandt found that pill-taking practices of patients contrasted with professional prescription, as patients adjusted prescribed medication timing and the number of medications whenever they missed doses, took drug holidays, and started and stopped taking pills at their discretion or in relation to how it fitted with their everyday lives.

The existential dimension to adherence to HIV treatment, as Stevens and Hildebrandt observed, is structured around the contexts in which patients lived and the meaning and consequences of the therapy for patients in terms of existential angst and loss of self. This observation was further articulated when Izugbara and Wekesa (2011) studied the beliefs and practices of antiretroviral medication use among the urban poor in Kenya. Izugbara and Wekesa observed that people living with HIV skipped medications, took medications at the wrong time, and mixed antiretroviral medication with other local HIV remedies because they did not consider compliance as efficacious for HIV treatment. This demonstrated that people living with HIV did not think the prescribed treatment was effective and, therefore, had wider concerns with managing their condition other than adherence. However, there are a whole range of reasons people do not adhere, even when they do know that treatment is effective.

Unlike quantitative studies that focused more on the extent, causes and predictors of adherence, qualitative research has thus produced important insights that demonstrated the embeddedness of agency, meaning, and negotiations in medication-taking behaviour of people living with HIV. This position was further reinforced by Persson (2016), who observed that acting on clinical advice, misgivings about HIV efficacies and toxicities, feelings of being healthy and normal, perception of HIV drugs as a potential threat to health and everyday lives, loss of freedom and independence, and the association of ART use with illness are reasons people living with HIV in Australia gave for not taking their medications.

However, these qualitative studies have demonstrated similarities in relation to comparably smaller groups and are concerned with the lived experiences of medication-taking, including affective and emotional dimensions, that reflect the constitution of self, agency and rationality in people’s daily experience of medication adherence. What seems problematic in these studies revolved around three key issues. The first is that the terrain of adherence has changed fundamentally in the last 15 years following the development and approval of newer medications that have resolved the earlier form of complexity of the pill regimen that made adherence difficult to comply with, by re-formulating three or four pills into a single tablet to be taken once a day (Margolis et al. 2017). The second is that the boundary of adherence has shifted following this current regime of Undetectability equals Untransmittability (U=U) in HIV management, as adherence becomes more socially accepted by people living with HIV in their quest to attain undetectability, or achieve non-infectious status offered by undetectability. The current regime of U=U has altered the agentic disposition and the self of people living with HIV in the actualisation of non-infectious status offered by undetectability. Therefore, the social acceptance of U=U by people living with HIV could depict that adherence is central to the constitution of self, agency, and rationality in their daily experience of medication adherence as far as HIV management in the current epoch is concerned. The third is the growing recognition of contextual differences in the experiences of medication-taking, which made analysing and understanding adherence to be different across various contexts and locations (Hodes et al. 2018). In fact, most of the sociological research on ART adherence has been conducted in the Western countries, with literature on adherence to medicines in the Global South, especially in sub-Saharan Africa, to be comparably sparse in relation to the aforementioned countries.

Recently, some sociological studies on adherence, especially in Nigeria, have sought to challenge the dearth of studies in this domain, by exploring socio-behavioural factors of adherence and providing the basis for comparison with Western dimensions. The findings in these studies revealed that different factors such as malnutrition, poverty, religious commitments, forgetfulness, stigmatisation, drug side effects and cultural understanding of HIV are the socio-behavioural factors shaping adherence to HIV medications (Okoror et al. 2013; Jappah 2013; Oku et al. 2014; Ayuk 2017; Tocco 2017; Cornelius et al. 2018; Muoghalu 2018; Okunola et al. 2018). Despite the contextual factors and differences that shaped the medication-taking behaviour of people living with HIV in Nigeria, the insights in these studies have demonstrated the embeddedness of agency, self-regulations, negotiations, and rationality in medication-taking behaviour of people living with HIV. These insights also shared empirical similarities with the lived experience of medication-taking of HIV-positive individuals in a Western context, especially on forgetfulness, stigmatisation, and drug side effects. On the other hand, malnutrition, poverty, religious commitments, and cultural understandings of HIV are the specific factors of non-adherence that are specific to a Nigerian context. Therefore, qualitative studies on adherence might take different dynamics and patterns, depending on various contexts, yet the findings produced interesting accounts that are fundamentally different from that of quantitative studies.

Even though adherence has changed as an obligation over time following the therapeutic advances in the production of newer medications into a single pill, the qualitative approach to adherence offered new insights into the social context of treatment and medication use without being fully disengaged from the topic of adherence. These qualitative studies were designed to critique or justify patients' non-adherence to HIV treatment through its findings, thereby suggesting that these authors did not disengage from the biomedical agenda.

Adherence saves the lives of people living with HIV, and the lived experience would not be possible if people die due to a lack of adherence. Furthermore, the transition to the current regime of Undetectability equals Untransmittability (U=U) in HIV management might have provided a basis for adherence to be more socially acceptable to people living with HIV, in their quest to attain undetectability or achieve non-infectious status offered by undetectability. If adherence is instrumental to attaining undetectability, it could then be argued that adherence is recognised by people living with HIV as a much broader issue than simply taking medications.

In this regard, the desire to attain undetectability could be prioritised in daily management of their conditions than simply being concerned with the power dynamics between doctor and patients. Despite this positive nature of adherence in the current HIV therapeutic regime, adherence is just an aspect of HIV management, and there are other practices through which people living with HIV manage their condition other than just solely on adherence. Therefore, the public health focus on adherence as the determinant of HIV management ignores other arguably crucial aspects of HIV management. The implication of focusing on adherence is that other critical HIV support services such as advocacy, advice services and behavioural change interventions might be neglected or phased out. If HIV management is no more than adherence to antiretroviral medication, then a new perspective is needed to understand other ways through which people living with HIV manage their condition in a holistic way. This critique of adherence as a one-sided measure has been articulated in a growing number of sociological studies on medication-taking.

For instance, Helman (1981) observed that psychotropic drug use has symbolic meanings of ‘tonic’, ‘food’ and ‘fuel’ to the users. Helman’s study suggested that medications as material objects have the social lives and meanings of medicine that transcend beyond clinical/medical purposes. Following Helman’s research, the plethora of studies found medication as a: ticket to normality (Conrad 1985), a loss of control and independence (Shoemaker & Oliveira 2008), harmful, unnatural and artificial (Gabe & Lipshitz-Philips 1982; Britten 1996; Whyte et al. 2002; Webster 2009), and invokes feelings of antipathy, ambivalence and suspicion (Doran et al. 2005). These differing meanings attributed to medications evoke social interactions and relationships beyond simply following doctors’ instructions, and shape social relations (Cohen et al. 2001; Van der Geest et al. 1996; 2006; Whyte 2002). The implication of these studies to HIV medications is that the meaning of antiretroviral medications is deeply embedded within the social web of social relationships that shape how HIV patients interact and use them other than just complying with doctors’ recommendations. The meanings that HIV patients attributed to their medications, or other reasons/ways they manage their HIV conditions in different social contexts, can be seen as more than just adherence. Therefore, the biomedical notion of adherence/compliance is one-sided and not sufficiently broad enough as a concept to fully explain HIV management.

Generally, the review of quantitative and qualitative studies on adherence has revealed the persistent conflation of adherence and treatment as if they are the same. Adherence and treatment are separate, but are mutually shaping. Treatment is a care mechanism in its own right that may not require adherence, especially if the illness is less severe. For instance, if an individual has a headache or body pain, and it is recommended by the physician to take drugs for three days, the individual may not take the treatment on the second day if such individual is well and healthy, or not experiencing any discomfort or pain. However, in a chronic illness context, treatment requires adherence to be effective. Adherence is just one practice to aid and support treatment or to make treatment more effective, whereas there are other practices that patients undertake around their health to support treatment. In this sense, a broader concept that accounts for other practices in which HIV-positive individuals manage their condition to support treatment is required. Healthwork as another way (other than adherence) of managing HIV will be examined in the section that follows.

2.3.2 Healthwork as HIV management

The problem associated with adherence compelled sociologists to examine and look beyond the concept with respect to how HIV management can be explored and understood. Another perspective in the literature through which HIV-positive individuals manage their conditions is healthwork (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008). Mykhalovskiy and McCoy argued the notion of healthwork with a view to understanding a broad range of activities and practices that HIV-positive individuals undertake around their health other than just adherence (Mykhalovskiy & McCoy 2002: 24). Healthwork was conceptualised following the quest to explore the kinds of activities that infected HIV individuals do, that are not accounted for in social science discourses on HIV management. Through an interview and focus group study with 79 people living with HIV in Toronto, Mykhalovskiy and McCoy defined healthwork as the wide range of activities that HIV-positive persons undertake to look after their health. With this definition, healthwork was further operationalised in the context of obtaining medications, translating medical instructions into medication routines, and the modification of the treatment regimen in everyday routines. Other areas of HIV-positive individuals looking after their health include the following: the participation and recognition of pill time, meal preparations, dealing with healthcare professionals, concealment of pill-taking from others, finding a physician, and overcoming the feelings dread and revulsion that are beyond the ruling discourse (adherence/compliance) on health. This study, however, adopts the framework of healthwork as the starting point of analysis on HIV management.

Like adherence, healthwork was articulated to support treatment. This can be seen in the context of its operationalisation as ‘a range of hidden activities that HIV-positive people engage in around their medications’ (Ibid: 26). This operationalised definition of healthwork was grounded around a set of questions: ‘how people living with HIV obtain their medications, how they translate medical instructions into medication routines and modify those routines in the ongoing flux of their day-to-day lives, and how they recognize pill time’ (Ibid: 27). Nonetheless, the scope of healthwork is more encompassing than adherence, as an operationalised definition demonstrated different practices other than adherence that people living with HIV undertake around treatment.

Healthwork as a conceptual frame represents a promising step that demonstrates the alternative analytical and empirical pathway to explore the broad range of issues associated with HIV management. By taking a different approach, Mykhalovskiy and McCoy, however, opened a new analytical frontier that exposes adherence as just a facet of HIV management, thus reinforcing the argument of social scientists that the everyday management of illness goes beyond the biomedical conception of adherence.

Although the conception of healthwork was derived from a Canadian context, its depth and relevance are yet to be applied in other contexts like Nigeria, for instance. What seems to be problematic in the conceptualisation of healthwork is that its associated practices are rooted in the context specific or cultural milieu in which they are undertaken. This cultural milieu that underpins HIV management is the fundamental issue that might affect the application of healthwork in non-Western or non-Canadian contexts. If healthwork is framed within non-Western cultural practices, or if the conceptual frame of healthwork is subjected to a non-Western cultural context, would its operationalise definition hold? If not, where might this lead? The quest to explore these questions illustrates why exploring healthwork in a Nigerian context is vitally important in this study. In this sense, how healthwork is shaped by and manifested in Nigerian cultural milieu, and its consequences for everyday management of HIV, is a significant contribution of this dissertation.

Nevertheless, the remit of healthwork remains open to empirical investigation, as its associated practices vary from context to context, and the kind of illness or condition involved. The analytical utility of healthwork as a viable sociological concept is its usefulness in understanding how situated lived experiences of health are rooted in cultural and structural contexts in both Western and non-Western settings. This is because healthwork is a biographically mediated practice that is individually undertaken by people living with HIV within a cultural/structural domain to create a new regime of health management. The nexus between biography and social structure in shaping the situated lived experiences of health in different cultural contexts highlights the analytic value of healthwork as a specific sociological concept. In other words, by linking and situating the self-care regime of health management with the socio-cultural context of its practices, healthwork provides an analytical framework for theoretical and empirical research.

Therefore, an understanding of healthwork among HIV-positive individuals, that is grounded in Foucauldian perspective on governmentality and technologies-of-the-self, allows for the exploration of how meaningful practice of healthwork is mediated by the politically charged medical intervention that underpins the biomedical governance of the body in a self-regulatory pattern, a move which makes an important contribution to the sociology of health and illness.

2.3.2.1 Healthwork, Governmentality, and Technologies-of-the-self

The concept of healthwork as the practices that people living with HIV undertake around their health to support treatment in everyday life resonates more broadly with Foucauldian theories of governmentality and technology-of-the-self. Foucault's volumes of works on power, governmentality, and technology-of-the-self (Foucault 1973; 1974; 1977; 1986; 2007) have been instrumental in generating important ideas in the understanding of health and illness.

Foucault's theory of power contested the traditional understanding of power that emphasises force and coercion, and posited that power resides everywhere, especially in 'mundane day-to-day practices, dominant languages, obedient and reformed subjects and taken for granted irrationalities' (Ferlie et al. 2012: 340). Rather than regarding power as a repressive exercise, displayed by the state institutions (like police and law) that involve coercion, punishment, threats, and manipulation, it is seen as 'a relationship which was localised, dispersed, diffused, and typically disguised through the social system' (Turner 1997: xi) operating at a micro-level, especially by social care workers and medical and other professionals, and in everyday practices. Foucault posited that Western power was more interested in controlling and regulating population through consent, normalisation, and discipline, and this was regarded as 'governmentality'.

With governmentality, power is not directed towards forcing people to obey the will of the state institutions; rather, power as a means of social control is exercised through subtler means of regulation to produce self-regulating subjects or individuals that modify themselves or construct self (Joyce 2001; Holmes 2002; Hakli 2009; Reich & Turnbull 2018; Mulubale 2020a). In Foucauldian parlance, government means to conduct others and oneself, while governmentality means how to govern others and oneself. Hence, government is an activity that aims to affect, mould, or shape the conduct of an individual or a group, with a view to conducting and regulating the conduct of people (Coyte & Holmes 2006). Therefore, governmentality involves the 'specific ways that individuals and populations are governed at the micro-level, and how particular "behaviours" and "performances" are facilitated and encouraged which reproduce, at a distance, a particular ordered society under prevailing political rationalities' (Prince et al. 2006: 254). In this sense, the act of government has moved from state politics into the homes and lives of the citizens, and individuals undertake responsible self-government. This self-government of individuals is regarded by Foucault as 'technologies-of-the-self'.

The technologies-of-the-self is the techniques of how to deal with oneself, which permit 'individuals to effect by their own means a certain number of operations on their own bodies, minds, souls, and lifestyle, to transform themselves to attain a certain state of happiness, and quality of life' (Foucault 1988: 18). Governmentality produces technologies-of-the-self through a particular kind of subjectification, as modern regimes of power exist through disciplinary practices that produce particular subjects (individuals). This form of subjectification that governmentality produces, allows the subjects (individuals) to engage in responsible self-government that prioritises the disciplining of individual bodies and the enactment of an ethical self-care regime. The technologies-of-the-self, therefore, involve the governance of disciplining bodies through the ethics of self-care that are primarily personal.

However, the Foucauldian analysis of governmentality and technologies-of-the-self has been broadly extended by scholars in the domain of health sociology. In a health and illness context, Foucault's works on governmentality and technologies-of-the-self have provided a means of conceptualising and invoking neoliberal models of health governance that downplay and deconstruct the role of collective service provision. Neoliberalism is regarded as driving a project of 'rolling back' the state from traditional areas of intervention, and the extension of market relationships into public service provision and other aspects of society' (Prince et al. 2006: 254). By focusing on a self-regulation and self-care regime, the governmentality approach posits government as something that occurs at the level of the body, and thus emphasises individual responsibility and empowerment by assuming that ‘individuals have the choice, the capacity and the obligation to exercise such choices and responsibilities’ (Coyte & Holmes 2005: 156). With the upsurge of chronic health conditions globally (De-Graft et al. 2010), health has increasingly become more of an individual responsibility than a public issue, with individuals being expected and encouraged to participate in the maintenance of their own health.

Analysing healthwork within the framework of governmentality and technologies-of-the-self requires an understanding of the setting in which the practices of such healthwork is undertaken, which is the Nigerian society in this context. The practice of healthwork is made possible by the free antiretroviral therapy (ART) programme in the Nigerian context. The enrolment of people living with HIV in Nigeria into a free ART programme provided by the state and their continuous participation requires a set of rules and obligations on the part of the users (people living with HIV). A free ART programme, as an expression of governmentality, whilst administered by the state through healthcare organisations, is not coercively undertaken to ensure absolute compliance, even when compliance is the overall objective. The Nigerian state used a free ART programme to monitor the population health of people living with HIV (Tocco 2017) and ensure subtle compliance through self-governance.

Remaining healthy is one of the informal conditions of participating in a free ART programme, which people living with HIV agree with and they are expected to comply with the conditions by following adherence to their medications, and participate in post-treatment counselling and testing (Nguyen 2005). This obligation could be seen as a complex expression of self-governance that emerged following embodied engagement and participation in the free ART programme. Therefore, remaining healthy while on ART is a social obligation that demonstrates the expression of responsible citizenship (Nguyen et al. 2007; Nguyen 2009). With governmentality, a free ART programme produces the subjectification of individuals that are controlled by the Nigerian state, and is disciplined around medicalising clinical encounters by healthcare professionals, who ensure that individuals’ self-regulation of HIV management vis-à-vis healthwork conforms to the conditions attached to free ART programme participation.

Technologies-of-the-self, which Mulubale (2020a: 15) regarded as ‘the biomedical governance of the body in the realm of self-care’, depicts the usage of ART as a technology to manage health or HIV conditions in a self-care regime. This self-care regime that is expressed by healthwork is governed by government free ART, which produces subjects that orient themselves to state requirements on the prevention of the spread of HIV in social life. With technologies-of-the-self, healthwork is concerned about how free ART enables the performance of specific modes of self-care regime around health to support treatment for the users (people living with HIV). With healthwork, people living with HIV are obligated to observe, moderate, and monitor their own actions, behaviours, and practices through the operation of disciplinary power (Martin & Waring 2018). Healthwork is the expressivity of technologies-of-the-self in everyday management of HIV, facilitated by the neoliberal health regime. Thus, healthwork is the intersection of governmentality and technologies-of-the-self in this research, as people living with HIV on state-sponsored antiretroviral treatment are self-regulating their health as individual responsibility and disciplining of the HIV bodies (Petrakaki et al. 2018), by conforming to the rules and conditions for continuous participation in a free ART programme.

Foucauldian theories of governmentality and technologies-of-the-self provided a theoretical basis to situate and ground healthwork, especially in the Nigerian context. The theoretical underpinning spawned by this Foucauldian perspective reveals the deepest intersection of governmentality and technologies-of-the-self in producing subjects (people living with HIV) that undertake healthwork as part of individuals’ responsibility and a self-care regime in an HIV context. Despite this contribution, Foucault’s work can be critiqued in two ways. The first is the lack of engagement on the conception of self in an illness context. The self in Foucauldian parlance is constituted by subjectification through the means of governmentality. The notion of self-care does not inform understanding about the awareness and conception of self in the illness domain. The sense of self, which implies who a person is, how they see themselves and how others see them, is missing in Foucault’s theorisation. In the illness context, chronic illness disrupts the sense of self of ill persons, and it is this alteration or disruption in a patient's conception of self that paves the way for the enactment of technologies-of-the-self. This implies that the expressivity of technologies-of-the-self depends on the awareness and conception of self in illness, and the lack of engagement of this issue in the Foucauldian approach is one of the gaps that this study would address. Secondly, Foucault’s works on governmentality and technologies-of-the-self focused on the body as the site of disciplinary power, self-regulation and self-care regime, but this does not address the issue of embodiment or corporeality in an illness context. The enactment of discipline and self-regulation on the body obscures patients’ awareness of their bodies and the experience of embodiment or corporeality in the domain. Sometimes, patients resist taking their medications daily (Chamberlain et al. 2011; Murdoch et al. 2013; Norris et al. 2013) and such resistance is not only against governmentality, but it is also the expression of embodiment/corporeality. It is the awareness of the new corporeality that patients or ill persons are taking on following the onset of chronic illness that would lead to releasing their bodies to the gaze of the medical profession, enactment of technologies-of-the-self, or be subject to governmentality. Therefore, the awareness and construction of corporeality in an illness trajectory, especially in HIV, which is missing in Foucault’s works, would be addressed in this research. These critiques of Foucauldian perspectives in relation to healthwork offer a critical pathway to examine the broader critique of healthwork, which is biographical disengagement, and which is to be explored in the section to follow.

2.3.2.2 Biographical disengagement: A critique of healthwork

One of the criticisms that can be levelled against Mykhalovskiy and McCoy’s (2002) conception of healthwork is the failure to articulate the timing of healthwork. The question of when to start engaging in healthwork by chronically ill or people living with HIV was obscured in the works of Mykhalovskiy and his colleagues (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008). In this study, healthwork begins by following a HIV diagnosis. In line with the articulation of Mykhalovskiy and his colleagues, healthwork in the Nigerian context is seen as the kind of practices undertaken around health to support treatment. After diagnosis, the practice of healthwork ensues when HIV-positive people’s trajectories are influenced by experiences related to their conditions, but also to their personal life expectations, resources available to them, and the demand from society (Martin & Peterson 2009). In this regard, healthwork is undertaken when people living with HIV come to terms with these factors when managing their conditions in daily life. Therefore, the experience of having HIV, and the response and living with its social consequences in daily life, are the biographical issues that are central to the practice of healthwork, and a discussion on healthwork would be incomplete without understanding the biographical issues that underpin its practise.

Therefore, there was a lack of engagement on the effects of healthwork on the biography of people living with HIV. Studies on healthwork to date only focused on post-diagnostic health practices that obscure the biographical dimension of HIV management as a serious area of sociological investigation. This is because healthwork depends on the diagnosis of a condition, and diagnosis has serious effects on biography. Therefore, healthwork may have a serious effect on biography. HIV, like other chronic illnesses, disrupts daily activities of its sufferers and facilitates discontinuity in their biographies (Bury 1982; Corbin & Strauss 1987). Accompanying the unfolding of a HIV diagnosis are a host of biographical consequences that will affect, to some degree, the healthwork that infected individuals will undertake. Healthwork is thus central to how people incorporate and respond to chronic illness in their lives and makes a presentable biography by living with it (Radley 1989).

Since healthwork is being undertaken in HIV post-diagnosis by healthcare professionals, the balancing act in managing the post-diagnosis reality within the individual's biography constitutes what healthwork seeks to achieve. In this sense, healthwork is the post-diagnosis practice undertaken to reorganise and work on the disrupted biographies of chronically ill persons, and that might change over time and across the illness trajectory. Therefore, a sociological exploration of healthwork would not have any purchase if its synthesis and articulation is not tailored towards mapping its effects on biographical consequences of HIV management in everyday life. This study expands the notion of healthwork to incorporate biography as far as the management of HIV in everyday life is concerned, in the section that follows. By expanding healthwork, the study fills the lacuna in its original conceptualisation, and then explores the consequences that healthwork posed to the biographies of HIV-positive individuals.

2.4 Expanding Healthwork

Expanding healthwork involves understanding the consequences of healthwork on the biography in everyday life, as this will help to deepen the lay perspective to a better understanding of healthwork. The biography according to Corbin and Strauss (1987) consisted of three major dimensions: biographical time, the body, and the conception of self. These three elements of biography form a whole called the BBC chain. The combination of these elements, which are parts of the criticism levelled against Foucault's works on governmentality and technologies-of-the-self above, gives an individual structure and continuity at any instant of an individual's life. When the chronic illness ensues, it breaks this BBC chain. This means that several alterations, changes, and disruptions occur in the biographical time, body, and the self, following the diagnosis and onset of chronic illness. This notion of biographical disruption articulated by Corbin and Strauss is an extension of Bury's (1982) work, to expand on what constitutes biography in an illness context and how the onset of illness disrupts such biography.

If Bury's work on biographical disruption is situated in Corbin and Strauss' articulation, then the disruption of one's former assumptions and behaviours, disruptions of social relationships, changes in one's self-concept, and the disruption of the cognitive and material resources available to individuals, including helping networks in Bury's parlance, are the disruptions of elements that constitute biography such as biographical time, the body and the conception of self and Identity. In this sense, HIV diagnosis and onset disrupt the biographical time, the bodily construction, and the sense of self and identity of people living with HIV/AIDS.

However, the claim that HIV is the major event that disrupts the biography has been contested by Ciambrone (2001) and Brandt (2008) following their observations of people living with HIV in the United States and South Africa, respectively. Ciambrone observed that women living with HIV did not consider HIV to be the most devastating event that radically altered their lives. Rather, assault such as domestic violence, mother-child separation, and drug use were deemed more disruptive than HIV infection. Ciambrone contended that a disadvantaged status such as being women of colour and racial status, together with negative life events such as and violence and substance abuse, may abate the impact of HIV/AIDS. Drawing on Ciambrone's work, Brandt (2008) observed that HIV was less disruptive than the poverty faced by women living with HIV in South Africa. It was found that social circumstances of poverty, inadequate food and poor housing conditions were the most disruptive to HIV infection. Brandt contended that HIV was a disruptive event to the participants, but such disruption was limited only to the time of initial diagnosis but not the post-diagnostic lives of the participants.

The observations of Ciambrone and Brandt are part of the limitations associated with the theory of biographical disruption, with respect to how previous research on illness and biography is sometimes dislocated from wider social and cultural issues. These criticisms of poverty, domestic violence, poor housing conditions and other factors observed by Ciambrone and Brandt are the social circumstances in which the participants live their present lives (present means at the time those studies were conducted). Therefore, poverty, domestic violence and other issues observed in the two studies are social and cultural issues that constitute the present circumstances of the participants, and this is connected to the broader biographical time (temporality) of the participants.

The implication of this reveals that Ciambrone and Brandt’s critiques are limited to biographical time, and do not have connection with the body and self, which are part of the biography that are disrupted by the onset of HIV in this study. In fact, HIV has shown to be disruptive to the sense of corporeality (body) and the self/identity, as several studies have shown (Flowers et al. 2006; Baumgartner 2007; Smith & Mbakwem 2010; Seeley et al. 2012; Freeman 2016). This is because, when HIV ensues, it challenges the previously held assumption and sense of the infected individuals as being healthy, and changes the sense of corporeality, self and identity as unhealthy persons (Wekesa & Coast 2013). In the corporeal realm, HIV changes the sense of infected individuals, as a person having HIV body and their corporealities are different from when they have not been diagnosed with HIV (Brouwer 2005; Persson 2005). Furthermore, by seeing themselves as unhealthy persons, HIV changes the identity of infected individuals to an unhealthy identity and questions the sense of themselves as an unhealthy person (Wekesa & Coast 2013). Therefore, the application of biographical disruption in this study is not limited to biographical time, but the disruption brought to the corporeal sense (body) and conception of self/identity of people living with HIV.

Expanding healthwork to accommodate biography requires alternative strategies to biographical work in reconstituting or putting back the broken/disrupted BBC chain. According to Corbin and Strauss, when chronic illness intrudes into an individual's life, it breaks down the BBC chain of the ill persons and alters the course of their biographies. Biographical work therefore consists of 'putting the BBC chain back together'. In other words, biographical work involves the 'review, maintenance, repair, and alteration' of an individual's biography in light of their changed reality (Corbin & Strauss 1987: 264). This means that several changes must occur in the body, self and biographical time such that old objects, especially the body and self, must be reconstituted or given a 'new meaning' in the light of a new illness reality (Faircloth 2004).

In other words, biographical work is the 'actions taken to retain control over the life course and to give life meaning again' (Boeije et al. 2002: 881). By resorting to biographical work, the ill person begins to appraise their illness situation to establish continuity and forge a new sense of memory between various aspects of his/her past and present life (Ville 2005; Felde 2011), as old objects (including body and self) are reconstituted or given new meaning, while the new objects are 'sought and discovered' (Corbin and Strauss 1987: 264). The sole essence of undertaking biographical work is to facilitate biographical reconstitution, which involves regaining a sense of wholeness that was lost when the links of the BBC were shattered. In this sense, the task of rebuilding the broken/disrupted BBC requires biographical reconstitution, which biographical work is committed to achieving. However, the BBC framework has been critiqued for its individualism because of the biographical work that is individualistic, personalised and limited to the affected individuals (Roberts 2000; Fielde 2011). In other words, the quest of biographical reconstitution vis-à-vis biographical work is thus undertaken by the individuals involved without any broader connection to the social aspect of illness management. It is the position of this study that reconstitution of the altered or disrupted biographies of the people living with HIV cannot be undertaken solely by internal mechanisms of biographical work. This is because the internal mechanism here means something that is central to an individual's cognitive or psychological state. Therefore, biographical work is subjective and restricted to the individuals involved. Rebuilding and reconstructing the disrupted biography require more than biographical work and, in fact, cannot be undertaken without the help of actions, activities and practices that are within and outside the internal/subjective state and normal daily routine (Hyden 1997) of the patients (which healthwork represents), and which are rooted in the culture and society in which individuals find themselves in.

Therefore, the biographical reconstitution that would ensue following the alteration and disruption brought by HIV can only be undertaken by healthwork that involves the combination of internal and external factors. It can thus be concluded that it is the biographical work that is personal-oriented and individualistic, not the BBC. This is because the elements of the BBC chain are not limited to individuals in orientation and outlook.

Extricating the BBC framework from the criticism of individualism has helped to provide a firm basis for theoretical direction for this study. The BBC chain is a suitable framework for this research because of its relevance to the African context. HIV studies in sub-Saharan Africa have demonstrated how elements of the BBC are collectivistic rather than being individualistic (Rohleder & Gibson 2006; Goudge et al. 2009; Flowers 2010; Naidu et al. 2012; de Wet & Wouters 2016; Ogunrotifa 2021). The BBC framework is useful to this study for two reasons. The first is that specific circumstances of the Nigerian epidemic are more collectivistic, like other parts of sub-Saharan Africa, where HIV prevalence is higher than that posited by the critics of the framework. The second is that personal emotional histories of people living with HIV affirm the dialectical relationship of individuals to society and, thus, relate each element of the BBC chain together by connecting the temporality, corporeality, and the conception of self of individuals in a wholistic account of life experiences. This indicates that the critics of the BBC framework have not taken the African collectivistic tradition into consideration, as specific circumstances of the Nigerian epidemic are more collectivistic, as in other parts of sub-Saharan Africa, where HIV prevalence is higher. For instance, Mulubale’s work on temporality and identity (Mulubale 2019; 2020) has revealed how people living with HIV in Zambia constructed their self based on the existing reality of the present and ongoing uncertainties about their desired futures, and how such self-construction is driven and shaped by medical factors, but play out through social relations with others in the society (Mulubale 2019). The embedding of temporality and self in the HIV context is experienced individually in a holistic pattern and shaped by the larger social relations, but not on its own terms. In a related work, Mulubale (2020a) observed that people living with HIV in Zambia concealed their HIV status to be socially accepted, due to the absence of standard social security and stigma. The implications of this finding can be seen in three ways. The first is that concealment of a participant's HIV status suggests concealing their HIV body from the gaze of cultural imagination that fosters discrimination and stigmatisation. The new corporeality that the participants constructed around their HIV status through concealment means that their HIV corporealities are rooted in cultural inscription. The second is that concealment of HIV status implies that the sense of their selves has been affected by the potential social reaction to their HIV-positive status, and hence the participants do not want others to see them differently.

The third is that being HIV-positive in Zambia constitutes an internalised form of identity, that is partially shaped by external social forces, and this underpins their personalised way of reacting to HIV positivity. In this sense, identity is individually experienced but is being shaped by the larger social forces that are outside the purview of the individuals. The implication of Mulubale's findings has revealed how African reality has refuted the facile charge of individualism levelled against the BBC framework, which is central to the understanding of biography in this research. The insights drawn from Mulubale's work have highlighted the interplay of individualism and collectivism (society), as a way of understanding the constitution of biography in a HIV context.

Subsequently, the African philosophy of Ubuntu contradicts the criticism of individualism levelled against the BBC framework, and thus affirms the collectivism that structured the cultural embedding of self and identity in the African biographical context. Ubuntu is defined as 'being human through other people' (Mugumbate & Nyanguru 2013: 83), and it also means that 'a person is a person through other persons' (Mwaanga & Banda 2014: 175). The meaning of Ubuntu depicts that an African person is not only an integral part of society but is inseparable from the community. The individuality and personality of an African person cannot be formed without the influence of his/her community. In this case, the biography of an individual, as well as his or her personality, are shaped by the social relations that are borne out of the community. The Ubuntu philosophy has profound implications for the understanding of self and identity in the African context. This indicates that how the communal sense of social existence shapes an individual's sense of self and identity is the interplay of how culture, history and society affect how we define ourselves and our experiences. An individual’s sense of self and identity is not only affected by the social context in which the individual lives, but forged due to the complex relationship that exists between the individual and the wider society (community) in which the individual is part of. Since the body is self, as Synnott (1993) argued, and the body is the site where self and identity are formed and expressed, it means that the corporeal construction of one’s body is shaped by the societal definition and construction of the body. The notion of Ubuntu has highlighted the saliency of society, culture, and history in shaping one’s sense of biography, and demonstrated the importance of collectivism, as the basis of contextualising the BBC chain in an African setting. Therefore, the Ubuntu philosophy has rebuffed the critique of individualism, and provided a useful justification for the adoption of the BBC framework in the Nigerian context, as far as this research is concerned.

As Mills (1959) noted, private troubles often constitute everyday problems, not only in the social world but also in illness contexts. The biographical issues associated with illness (such as biographical time, the body, and self/identity) are part of the private troubles that constitute everyday problems for people living with HIV.

What are the consequences of healthwork on biographical issues that HIV-positive persons face in everyday life? In addressing this overall research question in this study, healthwork needs to be expanded by employing and incorporating the idea on biographical work (Corbin & Strauss 1987; 1988; Boeije et al. 2002; Faircloth 2004; Ville 2005; Felde 2011) that addressed the disrupted episodes in the everyday management of the HIV condition. The significance of this in this study is to link healthwork with previous studies in the sociology of chronic illness, especially on biography. This will help to expand the concept of healthwork into the territory of biographical work, as part of the reasons why HIV-positive individuals manage their conditions in ways other than just through adherence.

Biographical work ensues in the aftermath of HIV diagnosis, as diagnosis becomes part of the texture of the biographies of people living with HIV. The starting point of HIV management is the incorporation of HIV diagnosis as part of the life stories of infected individuals. Therefore, diagnosis is something HIV-positive individuals would have to take into consideration in their everyday lives and practices. The HIV diagnosis is automatically placed into the biographical contexts of patients who accepted the diagnosis, as a requirement of managing their conditions in everyday life. Following the biographical disruption caused by the onset of HIV, reconstructing one's biography, the body and self/identity following the onset of chronic illness is the work that people living with HIV undertake around their health in everyday life.

Therefore, healthwork is rooted in patients' biographies and, by incorporating biographies, healthwork is extended beyond its initial definition. The implication of this conceptual expansion suggests that the kind of activities or practices that people do around their health and treatment, as articulated by Mykhalovskiy and McCoy above,[8] coalescence around engaging in healthwork to reconstitute the disrupted biographies, or the broken BBC chain that constituted a gap in Mykhalovskiy and McCoy's original conceptualisation.

By grounding healthwork through the framework of biographical work, this chapter delves into the roles of biographical time, the body/embodiment, and the conception of self and identity as the key concepts shaping HIV management in everyday life. In this sense, the expansion of healthwork in relation to the biographical context will now include the consequences and effects of healthwork on the biographical time of HIV-positive individuals, the impact of healthwork on the body(corporeality), and the effects of healthwork on self and identity as far as HIV management is concerned.

Since HIV diagnosis disrupts the biographies of the infected individuals, research on how to reconstruct such biographies (biographical work) has been extensively discussed in sociological literature on chronic illness. However, the consequences of healthwork on biographical components of HIV-positive individuals constitute a new gap in the sociology of chronic illness. This gap cannot be fully understood without reviewing/understanding the state of knowledge on what has been done within the context of HIV management in relation to biographical time, the body, and conceptions of self (identity). This is what the subsequent section in this chapter will be devoted to undertaking.

---

[8] As discussed above, the kind of activities and practices that people living with HIV do around their health include individual/personal choice of finding physicians, experience of managing medication regimens, the use of treatment information, experience of dealing with healthcare professionals and participation in activities of community-based AIDS.

2.4.1 Biographical time and healthwork

The use of healthwork has significant temporal sequences in the lives of people living with HIV. How is temporality experienced by people living with HIV? This question is not a trivial academic matter, but the answer to it has very real implications for HIV management. Temporality has different facets, and biographical time constitutes one of the forms of temporalities experienced in HIV management (Jowsey 2016). This is because temporal sequences are woven into the biographical fabric of HIV-positive people, in their participation in healthwork in everyday life.

The management of HIV in the era of HAART has profound consequences on the biographical temporalities of the infected individuals (Pierret 2001). Previous literature on HIV as a chronic illness has raised the question of how HIV diagnosis disrupted the biographies of HIV-positive individuals. This study will outline the relevant findings of these studies later in this section. However, there is a dearth of research on how post-diagnosis activities help in regaining continuity in the disrupted biographical lives of people living with HIV. This gap represents an important question that is crucial towards understanding the implications of healthwork on biographical time.

Biography in sociology is not simply about the study of individual life (Robert & Kyllönen 2006); rather, it connotes streams of life activities and events that are woven around past, present and future trajectories of an individual. Since biography involves elements of the past, present and future anticipation, biography then revolves around time and temporality.

Biographical time is, therefore, composed of ‘present and future over the course of a life; plus, a person’s perception of time, at any moment within the life course; plus the use of clock time (a day, week, year) in the performance of biographical or trajectory related tasks’ (Corbin & Strauss 1987: 253). Successful incorporation of the past, present and future is paramount to continuing life activities as far as the management of chronic illness is concerned (Sveen et al. 2016). As Corbin noted, the intrusion of illness into one’s life often results in the disruption of biographical time, where the ill person is forced to compare the body of the present and future with that of the past, therefore ‘resulting in a profound sense of loss and changed identities’ (2003: 259).

In sociological studies of HIV, biographical time is implicated in managing the consequences and impact of the condition in the everyday lives of HIV-positive people, such that people living with HIV make sense of their past and present events and future expectations in light of disrupted circumstances caused by HIV diagnosis. These circumstances through which biographical temporality is woven into the fabric of HIV management were first noted by Carricaburu and Pierret (1995), who articulated the way in which HIV-positive men engaged in calculated risks as palliative strategies to mitigate uncertainty that follows the consequences of HIV infection for everyday management. Through risk calculations, HIV-positive individuals exercise control over their lives as a way of projecting their lives into the future and refusing to be taken prisoner by illness in the present phase.

The work of Carricaburu and Pierret, however, found important echoes in Michele Davies' (1997) research on biographical time, who explored how HIV shaped infected individuals' sense of time and how it affected their lives generally. Following interviews with 38 people who have lived with HIV for at least five years prior to the advent of HAART, Davies found that HIV causes disruption of routine temporal orientations and assumptions that existed prior to HIV diagnosis. HIV diagnosis condemned individuals to the present and disallowed their freedom of future projections. While Davies considered a routine future projection as the general nature of human life, the certainty of death rendered it impossible for HIV-positive persons to find enjoyment in the present and be creative of possibilities necessary to make meaningful sense valuable to their future lives.

Davies' analysis of uncertainty emphasised the temporal assumptions that existed following HIV diagnosis. This uncertainty, which was folded into three temporal orientations, was adopted as part of the ways of dealing with HIV positivity. The first is that many HIV-positive persons developed the philosophy of the present that emphasise the need to reflect and utilise one's present interests and preferences. Second, HIV-positive persons did not allow the diagnosis to ruin the plans they previously held for the future and would refuse to relinquish their routine future orientations, thereby refusing to entertain the possibility of their imminent death. The third are those who felt they are living in an empty present and, thus, incapable of committing themselves not only to long-term plans, but present activities and relationships as well.

However, most of the participants in Davies' study were diagnosed with HIV in the mid-1980s when the AIDS onset was acute and rapid, and infected people faced imminent death and lived only a few months after diagnosis. It is not long into a conversation on biographical temporality and HIV management before Janine Pierret's (2001) work on the relationships between biographical time and identity in the pre-HAART era is mentioned. Pierret interviewed 30 HIV-positive persons who had been living with the condition for an average of nine years in Paris between 1996 and 1997 when protease inhibitor drugs were starting to be widely prescribed. Pierret was interested in understanding how a sense of time came into play in the long-term situation of life with HIV-positive individuals, and found that people living with HIV maintained life's continuity by living their lives in past trajectories and using the past to find explanation for their present situation. The past was found as a significant temporality, which was useful in reconstructing a sense of identity prior to HIV infection, and more generally for the life of the HIV condition characterised by uncertainty and death. By utilising the notion of an 'uncertain time', Pierret observed that the temporal constructions of HIV-positive individuals can coalesce around four typologies: *living from day to day*, *living 'an identical present'*, *living an 'empty present'* and *living with a 'possible future'*. For the participants, living day to day means placing importance on living their immediate present or moment without thinking about tomorrow. The participants who lived an identical present are those who continue living the life they had before the infection, and ensure that things stay the same irrespective of the cost that HIV poses to their present lives. The participants who lived an empty present are those who are yet to reconcile the depth of the rift opened in the everyday lives by HIV infection and their present reality of living with HIV. The rift caused by HIV infection was so deep that it could not be mended by the maintenance of a degree of normality, as though everything was the same as before the diagnosis occurred. Living with a possible future is the experience of participants who regarded the past as gone, but believed that their future would be great. Hence, they are consciously preparing for future possibilities, by initiating many plans such as re-enrolling in college, setting up a business, or even bearing a child. The striking similarities in the empirical works of Davies (1997) and Pierret (2001) can be seen in respect of the tendency by HIV-positive persons to be living on an empty present as consequences and challenges of living with the condition in everyday life.

Both works by Davies and Pierret were undertaken prior to the advent of HAART and, thus, obscured the role of HAART in shaping and reshaping the constructions of biographical temporality in HIV management. Nevertheless, Pierret attempted to address this gap in her subsequent study (Pierret 2007). Through the synthesis of qualitative data from three research projects carried out in France, Pierret sought to analyse changes in the experiences of persons living with HIV during the 10-year period 1990–2000. Pierret found that people living with HIV account for changes in their lives over time and in relation to the discovery of new treatments in 1996 by developing a three-fold typology: continuity with drawbacks, discontinuity and reversal, and withdrawal.

Participants that experienced continuity with drawbacks are those who maintained continuity with life prior to infection and were socially and occupationally integrated with their jobs, despite the uncertain prospects of living with HIV. To these participants, occupation represented the very meaning and condition of a ‘normal life’ and did not consider HIV as a stumbling block to their plans for switching jobs or occupations or searching for employment. Participants who experienced discontinuity and reversal are those whose chaotic experience of instability, caused by the onset of HIV infection, eventually led them to a new choice that marked a break with their previous life, and they did not consider reversal to the previous way of life as the way of living with HIV in the present epoch. The participants who experienced withdrawal are those who are struggling hard to come to terms with the present reality of having HIV and finding meaning to justify why they are infected with HIV. Due to their inability to find explanations as to why they are infected, they consider themselves as ‘useless’ and ‘idle’, and later retreat into silence and cut themselves off from their social/business contacts.

The use of a longitudinal design in Pierret’s work was the significant strength of the research and further represented an important way of looking at biographical temporality, by analysing changes in the experiences of persons living with HIV during the 10-year period (1990–2000) studied. Nevertheless, the gap in Pierret’s study revolved around two reasons: first, the qualitative data used in the study was drawn from three previous studies to make a comparison in terms of the experience of living with HIV in the pre-HAART and HAART eras. The data obtained did not focus on biographical time as the basis of exploring the experience of HAART. Second, the data that the study relied on, to analyse the experience of new treatment (HAART), was obtained via interviews conducted between 1998 and 2000. Since 2000, significant developments have taken place with HAART that have made most of the findings of Pierret to be less significant in a contemporary epoch. Pierret’s (2007) study revealed interesting findings that account for how changes in the lives of the participants were connected to how they formulated their account of their past, present and future around: continuity with drawbacks; discontinuity and reversal; and withdrawal. Yet, HAART was not sufficiently grounded and utilised as the basis of exploring the consequences of HIV on biographical time.

Generally, the review of the studies on biographical time and HIV has shown that most of the participants are those who have been diagnosed prior to 1996 when HAART was introduced. If the respondents were diagnosed during the HAART era, would the consequences of HIV on biographical temporality be similar to those who have been diagnosed prior to HAART? The answer to this question is unknown, as many therapeutic innovations have emerged since the introduction of HAART. In fact, recent developments in the medical success of antiretroviral therapy warrants thorough re-examination of biographical time in the light of these new developments. This latest development in ART has not only prolonged life expectancy, but has helped to reduce the level of the virus in the body to an undetectable level, where HIV does not transmit sexually when having an undetectable virus status (Keogh 2017), and this has made previous studies undertaken in the pre-HAART era to be outdated.

This dearth of studies on the biographical temporality of HIV-positive individuals in the HAART era, especially in the Nigerian context, makes scholarly inquiry into this domain more germane. Also, the uncertainty implicit in biographical temporalities of HIV management in these studies was articulated around the effectiveness and efficacy of the treatment regime to fulfil pre-diagnosis future plans, and curtail uncertainty associated with death. Since uncertainty about the treatment regimen was emphasised as the basis of fleshing out the temporal orientations in the pre-HAART period, the effects of other health activities and practices undertaken by people living with HIV on temporal orientations about their conditions were obscured. Therefore, a new study is required to further uncover how biographical time is shaped by the healthwork that people living with HIV undertake around their health.

Furthermore, the findings in these studies that situate biographical time around the notions of continuity with drawbacks, discontinuity and reversal, and withdrawal, demonstrated that the effects of HIV diagnosis altered and disrupted the biographical temporalities of the participants, but not how healthwork helps in the reconstruction of disrupted biographical temporality of HIV-positive individuals. These questions represent the lacuna in studies on HIV and biographical time to date, and this study will further explore this concept and fill the gap in the literature. Exploring this question of how healthwork helps to reconstruct disrupted biographical temporality of HIV-positive individuals will help to understand the consequence of healthwork on biographical temporalities of people living with HIV. Also, the implications of these studies might have an impact on the understanding of biographical temporalities, associated with the uncertainty of the present and future of living with HIV in the pre-HAART era and not in the HAART epoch. This study seeks to address how HIV-positive individuals construct their experiences of biographical time in the HAART era, using the Nigerian context as a case study for this research.

However, biographical time cannot occur in isolation of the body. This is because the effects of the illness/condition on the body may shape how past events, aspirations and plans are symbolically reconstructed in lieu of the present bodily condition. Therefore, the situation of one's body in lieu of the present corporeal condition and the effect of healthwork may help in shaping how HIV-positive individuals reflect on the past, adapt to the present and further shape a future about their body. In the healthwork context, the body is central to temporality, while temporality is integral to the conception of the body. Therefore, the corporeality of HIV in relation to the management of the condition and the attendant healthwork that follows will be discussed in the section that follows.

2.4.2 The HIV body: Healthwork and the corporeality of HIV in everyday life

The body is central to our experience of health and illness and became the site where the reconstruction of biography after an illness diagnosis took place (Williams 1996; Joyce 2005; Sveen et al. 2016). This indicates that the body is the repository for healthwork, where the task of looking after health and regaining continuity in the disrupted lives of chronically ill individuals is undertaken. As the basis of our-being-in-the-world (Merleau-Ponty 1962; Shilling 1993; Turner 1995; Williams & Bendelow 1998; Nettleton & Watson 1998), the body is the medium through which we understand and experience the world, and where we experience different human corporealities, which is defined in this study as ‘‘the embodied, lived experience of being HIV-positive’’ (Persson 2013: 1066). As human, we assume different corporealities due to various actions we perform, and due to the circumstances and contexts we find ourselves in (Crossley 1995a; 1995b; Csordas 1995; Shilling 2001; Howson & Inglis 2001; Williams 2003). The corporeality that we appropriate following the onset of illness is different to the corporeality that we assume prior to illness and after the illness episode. This is because, whenever an illness condition ensues, the ill person experiences different corporealities, as he/she objectifies the body in relation to the new condition and relinquishes the old corporeality. When an individual is diagnosed with HIV, he/she assumes or appropriates the new corporeality following the acceptance of the viral condition as someone as having an HIV body (James & Hockey 2007). Following Monaghan’s (2005) notion of fat-male-bodies-in-themselves, this new corporeality that HIV-positive individuals assume could be regarded as HIV body-in-themself. Monaghan (2005: 90) argued that fat-male-bodies-in-themselves is a corporeality that ensues when ‘big bodies’ are negatively typified in public space as ‘overweight’ or ‘obese’. Therefore, the corporeality of fat-male-bodies is shaped by culturally pre-established typification used in ‘interpreting fat male embodiment’ (Monaghan 2005: 87). What this implies is that corporeality of fat-male-bodies is derived from having fat bodies, which is shaped by the cultural inscription of overweight or obesity. Therefore, the corporeality of fat-male embodiment is located within cultural, social, and moral universes. The fat-male-bodies-in-themselves is particularly relevant to HIV body-in-themself because of its engagement with embodiment or corporeality. HIV body-in-themself is a corollary of fat-male embodiment (fat-male-bodies-in-themselves) in an HIV context.

As HIV bodies-in-themself is the HIV bodies that are located within cultural, moral, professional, and social universes, the self is inherent in the body and the body is rooted in the self. This is because the appropriation of cultural understanding of HIV through felt or enacted stigma produced changes not in the exterior body surface, but in the interior self. Such changes in the interior self produce a corporeality of having an HIV body called HIV body-in-themself, in which the body is being defined by the gaze of cultural, professional and the social structure. The onset of HIV body-in-themself ensues when an individual is aware of his/her HIV-positive status (through diagnosis). In that sense, the newly diagnosed individual is having a corporeality of HIV body-in-themself because the infected body has been subject to the gaze of healthcare professionals, and that defines how the infected individual perceives his/her body. Therefore, HIV-positive individuals construct their corporealities of HIV body-in-themself when they are aware of having HIV bodies (through diagnosis). The cultural inscription of having HIV bodies could shape their reactions to HIV diagnosis. The enactment and expression of corporeality around HIV body-in-themself occurs when HIV-positive individuals appropriate cultural, moral, and religious understanding or biomedical explanations as part of their reactions to having HIV bodies. The corporeality of HIV body-in-themself ensues when HIV-positive individuals are confronted by the cultural inscription or exposed to the gaze of the social structure.

The corporeality of HIV body-in-themself is entrenched when the infected individuals consider the effects of having an HIV body and what impact that has on the individual's social environment, as well as the effect that the changes in their body might have on their potential earnings, patterns of everyday life with significant others (friends and family), and the consequent changes to social and self-identity that might follow (James & Hockey 2007). In this sense, the worldview of those with a HIV condition is remarkably different from when they are not diagnosed with HIV/AIDS. This is because new meanings and interpretations arise following the corporeality of HIV body-in-themself, which are derived from socio-cultural classifications and understandings of HIV as an illness that are available to them or which they are socialised into. Therefore, having a HIV body is emergent of a cultural elaboration and representation that is integrated into the reflection of the way HIV-positive people are culturally socialised into the way they think about their body following a HIV diagnosis (James & Hockey 2007).

The HIV body-in-themself, which is a corporeal appropriation of HIV infectivity, is deeply rooted and woven into historical, social, and cultural understandings of HIV as an illness. It is therefore pertinent here to examine the historical context of the corporeality of HIV body-in-themself with a view to situating the social and cultural understanding of the illness. When HIV/AIDS emerged in Nigeria in the mid-1980s, medications used to treat the illness were not only expensive but were also not readily available, and HIV became an acute illness with sure and certain death (Idoko et al. 2002). The body became the site where people's suspicion, doubt and confirmation of HIV/AIDS was enacted. Due to lack of medications, there would be multiple and ongoing changes in the body of people living with HIV, as the virus would take a toll on their bodies after a few years of being infected. HIV-associated weight loss and lack of medications hastened disease progression and contributed to the high rates of early mortality between 1986 and 2002 in Nigeria. Therefore, anyone diagnosed with HIV within this period would always await impending future bodily debilitation due to affordability issues associated with the cost of medications. Becoming thin/skinny or experiencing weight loss thus became a cultural sign of HIV infection and impending death.

In the Nigerian context, there are two markers of HIV on the body: weight loss and continuous illness (Khalil et al. 2004; Tamuno & Babashani 2011; Obiagwu et al. 2013; Akinboro et al. 2014). These markers of HIV are the signs of having HIV that were rooted in the cultural frame and inscription, and always culminated in discrimination and stigmatisation of people living with HIV. In cultural parlance, it is believed that HIV has no cure and anyone who is diagnosed with the virus has received a death warrant. Therefore, people often discriminate and run away from anyone suspected of having HIV, and the two markers of weight loss and continuous illness are the cultural frames used to legitimise the presence of HIV in people's lives, despite their unscientific nature. In instances where individuals experience any of these bodily markers and do not have HIV or are not diagnosed with HIV, it is the responsibility of the affected individuals to prove the community or society wrong, by demonstrating that being affected with such markers has nothing to do with HIV/AIDS.

In discussing these markers in turn, the physical deterioration caused by the virus on the body of people living with HIV was first observed through loss of weight (Matoti-Mvalo & Puoane 2011). For instance, due to the fear of losing weight and being stigmatised as having AIDS or being infected with HIV, Puoane et al. (2005) reported that black South African women are not motivated to engage in physical or dieting activity. In the Nigerian context, perceptions regarding body size and weight loss are increasingly associated with having HIV/AIDS, such that individuals who suddenly experience weight loss are being stigmatised in their community (Folasire et al. 2012; Adeiza et al. 2014). In this regard, the community perceptions underpinned by a strong influence of cultural ideals on an individual's perception of their body is the key to understanding the link between HIV and the body. Therefore, individuals, especially black African women, usually associate being overweight with happiness and the absence of disease such as HIV/AIDS (Mvo et al. 1999). In comparison with the Nigerian context, HIV/AIDS is characterised by severe weight loss among South African women (ibid). The quest to always maintain a higher body weight is synonymous with overcoming the stigma associated with illness and sickness.

In African culture, weight loss is often associated with illness rather than malnutrition (Stern et al. 2010; Matoti-Mvalo & Puoane 2011). The implication of this is that bodily perceptions are ingrained in the cultural understanding of HIV/AIDS, which is part of the broader dimension of the cultural understanding of health and illness. The cultural definition of health and illness is ‘not merely the absence of disease or infirmity’ as WHO argued (Larson 1996: 181); rather, what is health and illness is what society or culture defines it to be, based on bodily and physical symptoms. What is meant to be ill or healthy depends on cultural or societal definition, and this includes ‘the knowledge, perceptions and cognitions used to define, classify, perceive and explain disease’ (Langdon & Wiik 2010: 464). The definition of who is healthy and who is ill is shaped by cultural disease categories, interpretations and classifications, and the body is usually the site where such interpretations and classifications occur in the cultural domain. Therefore, weight loss is not only a reflection of illness, but it is also a reflection of having HIV in cultural parlance. This indicates that there are cultural definitions of good body and bad body, based on societal categorisation and definition of illness as far as signs and symptoms are concerned. Weight loss is the expressivity of a bad body in terms of the cultural definition of health and illness and is rooted in the cultural understanding of HIV/AIDS. Since HIV/AIDS does not have a cure, those who are living with the virus are usually defined as ill, even when they are asymptomatic or do not experience weight loss. The maintenance of an ideal body weight is the desire of every individual, whether they are living with HIV or not, due to weight-loss stigma associated with HIV/AIDS.

Secondly, in the early period of the HIV/AIDS epidemic in Nigeria, most people who experienced HIV opportunistic infections always experienced continuous/persistent illness, and they were often unaware of their HIV positivity. Continuous illness is an experience of a bad body in cultural construction and could, by extension, be one of the markers of the HIV body in a cultural context. Therefore, anyone who experiences continuous illness in Nigeria is usually suspected of having HIV due to the lack of a cure associated with the HIV (Igun 1988). When their HIV-positive statuses were later confirmed and treatment of HIV opportunistic infections ensued, such cases became the reference point for understanding the symptoms in medical, media and official government discourses and campaigns.

Over the years, continuous illness lingers in the imagination of the public as one of the symptoms of HIV/AIDS in Nigeria. Therefore, anyone who is experiencing continuous/persistent illness is suspected of having HIV, and people begin to avoid or move away from the infected individuals until they can demonstrate that their continuous illness is not caused or associated with HIV/AIDS. Experiencing continuous or persistent illness is a body marker of HIV in a cultural context.

These two markers attract discrimination and stigmatisation within the cultural frame of reference on HIV/AIDS in Nigeria. With free antiretroviral therapy in Nigeria since 2002, and the recent scientific transformation in HIV drug therapies that transformed HIV not only into a manageable chronic illness, but also to undetectable status, people living with HIV are still defined within cultural parlance as having a bad body, while undetectable people living with HIV are still regarded as ill people.

Therefore, the body is the most immediate and visible site of representation of HIV in the cultural domain, which was reinforced by the media understanding of HIV until recently. This mainstream media portrayal of HIV patients as lean and skinny individuals that faced excessive weight loss due to a lack of treatment, further heightened the negative public perception of the disease. Anybody who suddenly appeared lean, skinny, and experienced excessive weight loss are suspected to be living with AIDS (Smith 2003; Babalola et al. 2009).

The body then seemed to be actively involved in the way illness shapes identity, as HIV-generated identities (Flower et al. 2006) following the threat of AIDS lie in people’s perception and fears of the disease. The cultural understanding of HIV was that there was no cure for it and whosoever became infected with HIV got his/her death warrant at the time of diagnosis. Therefore, HIV was regarded as deadly, dangerous, contagious, and depraved (Sontag 1990; Joffe 1999; Persson 2005; Persson 2013). As a new terrifying disease, HIV possessed the ‘emergence of a disease whose charge of stigmatization and whose capacity to create a spoiled identity was far greater’ (Sontag 1978:16). Because of this, in most sub-Saharan African societies, especially Nigeria, HIV was regarded as a viral enemy that identified with evil and attaches blame to its victims (ibid).

Immediately after an individual is diagnosed with HIV, the individual’s perception of having HIV corporeality ensues, which indicates changes in the individual’s health status and that of the social identity for the affected individual following the social stigma that accompanies the debilitating physical manifestations (James & Hockey 2007). This new corporeality of HIV body-in-themself ushered stigmatisation of people’s identities, preventing them from seeking diagnosis at an early stage and marked sufferers out as deserving both a curse and punishment (Sontag 1978) for their previous lifestyle choices.

However, two decades after the introduction of HAART, HIV was more openly discussed in Western contexts, as felt stigma has reduced and people living with HIV have freely disclosed their viral status in the public space (James & Hockey 2007: 4). This disclosure of a personal HIV status is facilitated with the help of new drug therapies enabling HIV-positive people to live longer, and successful drug treatments are easily accessible. In this sense, the fear and stigma surrounding HIV/AIDS in the 1980s has now diminished in Western societies, as HIV is now regarded as a manageable chronic illness that no longer poses a death sentence for those affected by it (Siegel & Lekas 2002). However, in some African societies, especially Nigeria, the negative public discourse has not receded as in the Western context (Muoghalu & Jegede 2013). The mapping out of the HIV body, as the difference between diseased and contagious others, is a cultural contextualisation that found its expression in the moral branding of HIV as a disease that is easily spread through sexual transgressions and other ‘deviant’ practices (Persson 2005). The stigmatisation of the HIV body as infectious by others demonstrates how the onus of the burden of infectiousness and the spread of the virus lies with the infected individuals. Locating infectiousness towards others within the wider social context of HIV body-in-themself means that the body with HIV is still perceived as an infectious body that requires containment and precautions through discrimination, and the exclusion of infectious others from the public space.

With the recent scientific transformation in HIV drug therapies that transformed HIV into a manageable chronic illness, the HIV body still lingers in the cultural imagination in a Nigerian context. Despite this transformation fostered by HAART, sociological studies have examined how individuals assume different corporealities due to the circumstances and contexts they find themselves (Crossley 1995a; 1995b; Csordas 1995; Shilling 2001; Howson & Inglis 2001; Williams 2003; James & Hockey 2007), but the dimension in which the corporeality of HIV body-in-themself is assumed in the Nigerian context is yet to be explored. In other words, the question of how the corporeality of HIV body-in-themself is constructed in the Nigerian context by HIV-positive people remains a largely uncharted course for investigation. Exploring this question requires an understanding of how HIV-positive people perceive their HIV body in this era of HAART, especially in recent times where there are debates and claims that an effective HAART regimen can render HIV non-infectious (Vernazza et al. 2008; Vernazza 2009). This debate about whether an effective HAART regimen can usher in a non-infectious body and thus prevent the spread of the virus through unprotected sexual intercourse will be examined in the section that follows.

2.4.2.1 From Infectious body to non-infectious body

In cultural parlance, the HIV body is objectified as a ‘diseased’ entity ravaged by a virus that renders the affected individuals highly infectious. This corporeality of the infectious body, which was created through both a biomedical model and everyday interactions in socio-cultural settings, lingers in the cultural imagination for a long time.

In fact, HIV-positive people in most of the studies conducted share this cultural and public perception of their bodies as abject and infectious, which has thus prevented them from establishing viable social relations with others (Ciambrone 2003; Flowers et al. 2006). The infectious corporeality gained important recognition when Squire (2010) argued that the HIV-positive body denaturalises the infected people in cultural and public spaces, while HAART naturalises them into medicalised citizenship and normalises their health condition into a manageable ‘enterprise of survival’. Through the notion of naturalisation and normalisation, Squire highlighted the importance that the current HIV therapeutic advances played in circumventing and undoing the stigmatisation of the infectious body. Despite the naturalising and normalising act of HAART, the cultural imagination of HIV-infectious bodies has continued to dominate popular culture and mainstream headlines until recently, when a previous claim from a group of Swiss HIV experts challenged this perception – which, in turn, began to gain currency internationally.

In 2008, a group of Swiss HIV experts claimed that ‘an HIV-infected person on antiretroviral therapy with: undetectable viral load for at least six months; have no other sexually transmitted infections, coupled with effective adherence to antiretroviral therapy, is not sexually infectious, that is, cannot transmit HIV through sexual contact’ (Vernazza et al. 2008; Vernazza 2009). Despite the controversies and critique that this claim generated at the time of its publication, recent studies seemed to have validated the claims made in this statement by the Swiss HIV experts (Attia et al. 2009; Donnell et al. 2010; Cohen et al. 2013). Because of these studies, the idea taken from these Swiss HIV experts has now been woven into the very fabric of the current mainstream global HIV agenda of the treatment as prevention programme by global health agencies. The implication of this Swiss statement in HIV management is the shifting of cultural narratives from an infectious body to a non-infectious body as far as the HIV-positive body is concerned.

The Swiss statement, together with the global mantra of treatment as prevention, facilitated a creation of a new sort of corporeality in the discourse and framing of the HIV-positive body. This was captured more succinctly by Persson (2013), who extended Squire’s notion of normalisation to demonstrate how antiretroviral therapy has ushered in non-infectious corporeality. Persson argued that HIV treatments are not only effective and efficient in enhancing the survival, health and life quality of people with HIV, but are capable of reducing the amount of virus to undetectable levels in the bloodstream, and thereby reducing the risk of HIV transmission. Persson contended that antiretroviral therapy has brought about a shift in the embodied experiences of being HIV-positive, such that the treatment is increasingly considered so effective at viral suppression that it renders people with HIV as sexually non-infectious, regardless of the cultural inscription attached to the disease. The awareness of the non-infectious body is the expressivity of HIV body-in-themself that has been subject to the gaze of the occupational structure of healthcare professionals.

Other studies have confirmed the observations of Squire and Persson and demonstrated how ART had normalised the HIV condition by enabling childbirth, being able to work, engaging in unprotected sex, and having stable relationships, especially in Tanzania (Mattes 2014), Uganda (Seeley et al. 2009; Seeley & Russell 2010), South Africa (Robin 2005), and the UK (Mazanderani & Paparini 2015). However, the clinical claim of having a normalised life when on ART has been contested, especially in relation to psychosocial issues. Mulubale's (2019) study of people living on ART in Zambia observed that ART has transformed the HIV body into normalisation, but the medications have not normalised the stigmatised body caused by HIV diagnosis. Even when ART has improved the physical health and fostered undetectability, Mulubale noted that ART has not removed the stigmatised body and, thus, compounded the problem of disclosure 'that makes participants anxious about their status, making it an internal and mental health issue that can be associated with a lack of self-confidence and acceptance of living on ART' (Mulubale 2019: 152). In this sense, patients' sense of normalisation was significantly challenged by the moral dilemma (stigma) associated with the HIV body, despite having zero viral loads.

The finding of Mulubale has supported the observation of Young et al. (2019) about the global campaign on Undetectable equals Untransmittable (U=U). In July 2016, a group of clinicians, community and HIV organisations and researchers, under the auspices of Prevention Access Campaign, started a social media campaign tagged 'Undetectable equals Untransmittable' or U=U. With the media attention and publicity that this social media campaign generated, Young et al. (2019) noted that the campaign was limited towards stigma reduction around fear of transmission associated with HIV body, rather than concretely addressing the risk of HIV transmission despite undetectable viral loads. The findings of Mulubale and Young et al. have reiterated the promissory note of ART in normalising HIV body vis-à-vis the global campaign and discourses. Insights drawn from these studies has revealed that more studies are needed to evaluate whether ART, which fosters U=U, has really normalised HIV body in the everyday experience of people living with HIV. There exists a dearth of research in this domain in the Nigerian context, and this study seeks to address and explore this gap.

Moreover, what is central to the arguments of Squire, Persson and other scholars about the trajectory from infectious to non-infectious bodies is the emphasis on adherence to HIV treatment as the basis of achieving non-infectiousness. Adherence to antiretroviral treatment could be central to the corporeality of non-infectiousness, but achieving non-infectiousness cannot be reduced solely by adherence. Even though adherence fosters a lower viral load and higher CD_4 count, the biggest barriers to re-imagining the HIV body as a non-infectious corporeality are ingrained in cultural understandings as outlined above. Since this cultural understanding cannot be ignored in the understanding of HIV corporeality, this study explores how the cultural inscription of HIV impinges on the understanding of HIV corporeality, and the impact of HAART on these understandings. This portrayal, that understanding how cultural understandings shape non-infectious corporeality, requires more than just adherence. Therefore, this study will explore how a corporeal sense of HIV infectiousness/non-infectiousness can be shaped by the healthwork of HIV-positive people in everyday life, which has been under-studied in the sociological domain.

Despite the effectiveness of antiretroviral therapy in making the HIV-positive body harmless and non-infectious, HIV-positive individuals are still considered as ‘infectious others’ to those around them due to the cultural inscription of HIV body (Hallas 2009; Subero 2014; Pocius 2016), as previously discussed. As a result, the onset of HIV culminated into the corporeality of HIV body-in-themself that challenged the identity of HIV-positive individuals as ‘infectious others’ and altered their sense of self and the way others see them. Therefore, the sense of self and identity that was altered and generated by the corporeality of HIV positivity will be examined in the section that follows.

2.4.3 The conception of self in healthwork

In an illness context, the self is pertinent to the experience of health and biographical trajectories of illness. The primacy of self in healthwork is beneficial to the healing process and illness management in everyday life. It is within this context that self is fundamentally linked with the body and biographical time, in which none of the three components of biography can exist independent from each other. HIV does not only alter and disrupt the biographical time and corporeal sense of people living with HIV, but also disrupts their sense of self. Healthwork helps HIV-positive individuals to come to terms and incorporate their illness into their everyday life and routines, and thus enable them to fashion out how to reclaim the disrupted and lost sense of self. Self is how we see ourselves. Self, therefore, is the personhood that individuals internalise or form because of the participation of a person in structured role relationships (Baumgartner 2007: 919).

The notion of self, which emanated from a symbolic interactionist paradigm in sociology, has become one of the central concepts in the sociology of health and illness in the last four decades. Following the pioneering writing of Kathy Charmaz's *Loss of self: a fundamental form of suffering in the chronically ill* (1983), studies on how the self is affected by chronic illness has proliferated. Charmaz's corpus of work (Charmaz 1987; 1991; 1994; 1995) alongside the contributions of Corbin and Strauss (1987), Radley (1989), Kelly (1992), Kelly and Field (1996), Ciambrone (2001), Charmaz (2002a; 2002b), Pearce (2008), Lindsay (2009), Tausig (2013) and Tholts (2013), were undertaken in a wide range of studies on chronic illnesses such as cancer, emphysema, heart and circulatory disease, diabetes, chronic fatigue syndrome, arthritis, and other illnesses such as multiple sclerosis. These studies laid the foundation for the understanding of self in the health and illness domain up to now.

However, a critical review of these texts, together with contemporary works on self and chronic illness, revealed that self is articulated and utilised in a generic way, which obscured the reality of the kind of self that was involved in chronic illness conditions. This generic use of self in Charmaz's treatise was not sufficient in demonstrating and understanding the kind of self that was central to the discourse of chronic illness. Following the review of the kind of self that Charmaz and others utilised in exploring the impact of chronic illness, what can be observed is that this body of work explored the impact that chronic illness has on the pre-diagnostic self and, consequently, the authors are explaining the outcome, which is the post-diagnostic self. In other words, the impact of chronic illness on the post-diagnostic self was not studied in its own right; rather, the post-diagnostic self was discussed in the course of exploring the impact of chronic illness on the pre-diagnostic self.

The pre-diagnostic self is a self that individuals developed prior to illness, while the post-diagnostic self is the self that emerged following the diagnosis and onset of chronic illness. By focusing on the pre-diagnostic self, the understanding of what constitutes the post-diagnostic self following the onset of chronic illness is obscured. The self of an ill person is altered by the onset of a chronic illness, and such an alteration is woven into complex fabrics of who they are in the light of the new health circumstances they are experiencing (Kelly & Field 1996). In response to the chronic illness, the sick person may readjust their biography by incorporating the illness into their sense of the new self.

This onset of a post-diagnostic self was evident when Charmaz (1991: 257) acknowledged that the loss of self is the loss of a pre-diagnostic self in her subsequent work:

> Loss of self means being involuntarily disposed of former attributes and sentiments that comprise one’s self-concept as well as the actions and experiences upon which they are based. It also means losing the self-definitions with which one had most identified. With loss of self, earlier boundaries of the self-concept shrink and becomes permeable.

From Charmaz’s position, it is the post-diagnostic self that ensues following the lost pre-diagnostic self in this context. The expansion of Charmaz’s works and others here is the dichotomisation of self into the pre-diagnostic self and the post-diagnostic self. This dichotomisation would afford us the opportunity to demonstrate that the post-diagnostic self is the kind of self that is central to chronic illness management.

In the illness context, self is embodied and exists prior to illness. The self in illness is significantly linked with what ill persons think about, such as who they were before and during the illness. The questions ‘Why me’, ‘Why now’, ‘Who am I’ and others revolve around the conception of the post-diagnostic self—which reflects what ill persons think about themselves in illness situations as previously stated. Charmaz observed that the consequences of the loss of self are ‘leading restricted lives, experiencing social isolation, being discredited and burdening others' (1983: 168). These four consequences highlighted by Charmaz about the loss of self are simply the dynamics of the post-diagnostic self. This is because, immediately after the chronic illness and its onset begins, the pre-diagnostic self is disrupted while the patient's post-diagnostic self develops by incorporating the illness into their lives.

This was demonstrated in Charmaz's (1983) work, where it was deliberated that 'a fundamental form of that suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones' (Charmaz 1983: 168). The dynamics of the post-diagnostic self ensue when patients compare and evaluate previous and new assumptions about the world and how they see themselves during the illness experienced. This reality of the post-diagnostic self was further demonstrated in Russell and Seeley's (2010) articulation, that the onset of chronic illness led to a transition to a new sense of self where patients adjust 'towards incorporating a chronic illness into their lives, their identity, and their interactions with others, in their daily routines and their future outlook' (Russell & Seeley 2010: 375). Therefore, the post-diagnostic self is not static, but an ongoing experience that changes as the illness trajectory progresses.

Over the years, a number of sociologists have utilised the core ideas of Charmaz in their exploration of chronic illness such as ulcerative colitis (Kelly 1992), epilepsy (Scambler & Hopkins 1986; 1990), ileostomy (Kelly 1991), diabetes (Kelleher 1988), asthma (Adams et al. 1997), and chronic fatigue syndrome (Clarkes & James 2003). In the context of HIV, studies continue to rely on or over-emphasise the pre-diagnostic self as the basis of exploring self. The earliest published study appears to be Crawford's (1994) work on the boundaries of self and 'unhealthy' others. In unpacking how cultural stigmas associated with AIDS shape the stigmatised self, Crawford (1994) noted that health is a symbolic domain for creating and recreating self in cultural politics that defines the social meanings of AIDS to the infected individuals. The 'unhealthy' others, according to Crawford (1994), are those who are labelled 'contagious' and 'sexually deviant' others, who are symbolised as the negativism of AIDS and have become images that are mobilised in reconstructing self and shaping identity as far as HIV/AIDS is concerned. HIV-positive individuals are imagined by others as embodying all the properties of falling outside the domain of a healthy-signified self, associated with disease or being diseased. Crawford therefore concluded that the concept of health is central to a modern identity, such that the task of preserving social self as ‘healthy’ from a spoiled identity of HIV as being purely a sexually transmitted disease is sustained through the creation of ‘unhealthy’ others.

Therefore, Crawford’s findings on the notions of ‘healthy otherness’ and ‘unhealthy otherness’ have important implications in the work of Crossley (1997) who, following interviews with 38 long-term HIV survivors in the UK, explored the ways in which HIV-positive individuals construct their selves in relation to what they think about their diagnosis. Crossley found that HIV-positive individuals constructed self-images of ‘healthy survivors’ that are associated with a healthy self—of being a good, moral and responsible self. Those who do not share these characteristics are perceived as unhealthy, immoral, irresponsible and bad, in a bid to present an image of order and to protect themselves from a sense of vulnerability and perception of being infected individuals with a deadly disease.

By linking the notions of self and health with individual responsibility, Crossley’s findings of ‘healthy survivors’ and ‘unhealthy survivors’ aligned with Crawford’s notions of ‘healthy otherness’ and ‘unhealthy otherness’, thus providing important implications on how HIV is incorporated in the selves of the infected individuals. The loss of self stems from the loss of being healthy when comparing oneself with others in HIV management, and demonstrates the effects of chronic illness on the self in everyday life. The response to this loss of self could have a long-lasting effect on future plans and be devastating if intertwined with personal and domestic issues, as Ciambrone (2001) observed. Following interviews with white, black and Latino women living with HIV in the United States, Ciambrone found that being diagnosed with a potentially fatal and stigmatised HIV infection was a traumatic event that posed immediate threats to their sense of self and identity and had a lasting impact on their future plans and goals.

Ciambrone considered that, at diagnosis, the infected women equated HIV/AIDS with despair and death. This resulted in a situation in which several women wanted to commit suicide; but, as they integrated HIV into their biographies over time, they did evaluate HIV as the least disruptive event compared to domestic violence, mother-child separation, and drug addiction as the most disruptive problems they had to contend with in their everyday lives. These women's evaluation of traumatic events of HIV was relative to their other experiences, the consequences of which had potential biographical effects on their future aspirations.

These studies' findings illustrate the defining moment at which the post-diagnostic self becomes the basis through which the construction of self of the participants is forged. What is problematic in these studies is the extensive focus on the pre-diagnostic self and the lack of empirical engagement on the post-diagnostic self in the analysis of how HIV-positive individuals construct their selves, the same gap that was found in Charmaz's articulations.

Having expanded self into the pre-diagnostic self and the post-diagnostic self, then the question of how the post-diagnostic self is constructed by HIV-positive individuals following the onset of HIV in the Nigerian context represents a lacuna that is worth exploring. The exploration of this question will help to provide insight into the main question in this chapter, namely: What is the impact of healthwork on the self (post-diagnostic self) of HIV-positive individuals in everyday life?

When HIV diagnosis has been accepted by the patients, there is always a tension and struggle between the self and identity on the part of HIV-positive individuals (Green & Sobo 2000). Therefore, the self cannot be divorced from identity as a new identity (which is HIV identity) and created when a post-diagnostic self is developed. The self cannot be divorced from identity, as identity is created when the self is developed (Baumgartner 2007). Therefore, when considering the background research on the self within the HIV context, discussion of identity seems inevitable. This is because self-identifying as a HIV-positive person indicates that the HIV-positive person's self is identifying with a stigmatised condition. This is one of the claims Sandstrom (1990) made in his account of the consequences of HIV on the identity of the HIV-positive individuals. Sandstrom argued that negative self-feelings created by the HIV condition evoke a sense of confusion and uncertainty about the progression of the person's illness and make social meaning about AIDS-related identity possible. The incorporation of a stigmatised identity into self, as Sandstrom noted, involves constant construction and negotiations of the meaning of an AIDS-related identity into everyday life of the infected individuals.

Sandstrom concluded that such negotiations are entangled with social reactions caused by stigmatisation, nurturance, fear of contagion and death anxiety, which conspire to reinforce a wide array of interactional ambiguities, dilemmas, and threats to the self. For Sandstrom, HIV/AIDS is one of identities that HIV-positive individuals incorporate into their selves and everyday life. The impulse of HIV/AIDS identity as the primacy of self was further exemplified by Roth and Nelson (1997), who considered the consequences of HIV on identity as part of the wider process through which HIV-positive individuals relinquish their old self and adopt the worldview of the AIDS community. Roth and Nelson found that HIV diagnosis represents a significant phase in which identities of people living with HIV are formed. HIV diagnosis changes their status (identity) into HIV-positive personhood and constitutes a rite of passage into the AIDS community.

By using the notion of ‘identity as rite of passage’, Roth and Nelson demonstrated the nuanced way in which the identity of HIV-positive women in the United States were forged when they are automatically initiated into the HIV community following diagnosis, and the adoption of behavioural norms shared by fellow members of that community. Despite highlighting the significance of HIV-positive communities in the construction of HIV-positive identities, Roth and Nelson’s study did not unpack how people living with HIV adopt HIV-related identities.

As identity becomes a central issue in HIV management, the review of early sociological studies on HIV and identity focused extensively on gay men, the middle-class and white population, mostly in the United States, with little or no evidence from other countries (Sandstrom 1990; Roth & Nelson 1997; Tewksbury & McGaughey 1998). Yet, the impact of an HIV diagnosis on everyday lives of black Africans living in the UK was unknown until Flowers et al. (2006) explored it. Following interviews with 30 HIV-positive individuals in London, Flowers et al. (2006) found that HIV-positive individuals were struggling to come to terms with the irrevocable nature of the HIV disease. The meaning of HIV-positive test results has assumed a master status over other identities, and this has profound implications for family, partners, children, life expectancy, and future health.

Despite these impacts, Flowers and colleagues observed that HIV was not the most important or top issue in the everyday concern of HIV-positive individuals—as accommodation difficulties, separation from their partner and children, and a lack of money were their topmost concerns. Other concerns include problems in accessing social welfare, an appropriate diet, medical care, work, living without a passport, and the fear of being deported. Flowers and his colleagues observed that HIV diagnosis has the ‘productive capacity to generate identities’ as the HIV-positive individuals are battling to manage the fallout of a stigmatised HIV condition around identity rather than just their health.

Moreover, an insightful dimension was introduced into the research on HIV identity when Baumgartner (2007) explored the longitudinal process through which HIV/AIDS identities are incorporated over time. Through interviews conducted between 1995 and 2000 with 18 people living with HIV in the United States, Baumgartner (2007) identified three phases through which an HIV/AIDS identity is incorporated into the self. These are through the following: diagnosis, immersion and integration phases. The diagnosis phase is characterised by shock, denial, fear, relief, and the post-diagnosis era, where medical intervention is sought. The immersion phase involves acceptance of the HIV status by joining a HIV support group and immersion in the subculture of HIV groups and teaching others about HIV/AIDS. The integration phase is characterised by a period of life evaluation, and a balancing and disclosure of their serostatus.

The implications of Baumgartner’s findings indicate that temporality is an important factor in the incorporation phases, as time allows people living with HIV to incorporate HIV/AIDS into their identities following the diagnosis and widespread use of antiretroviral medications that enable them to live longer. The notion of temporality in Baumgartner’s work demonstrated how identity transition among people living with HIV can occur over time. Tsarenko and Polonsky (2011) illustrated this more profoundly following the interviews with 15 HIV-positive individuals in Australia. Tsarenko and Polonsky found that being diagnosed with HIV resulted in acquiring ‘undesired possession’ that facilitated the acquisition of a new identity. The identity transition process occurs when HIV-positive individuals attempt to detach themselves from this ‘undesired possession’ by taking ownership of their illness through the rearrangement of priorities, adaptation to the new state, and making unplanned decisions. Resorting to illness ownership allows the infected individuals to focus on their new lives and redefine their new identities, rather than just focusing on what they have lost when they became HIV-positive. By attributing identity transition to illness ownership, the findings of Tsarenko and Polonsky demonstrated that changes in identity over time following diagnosis are concomitant with how HIV-positive individuals redefine their identities, as HIV is seen as being a part of their lives rather than being seen as controlling their lives.

However, sub-Saharan Africa accounted for more than 70 percent of the global burden of infections (Kharsany & Karim 2016), yet the avalanche of studies reviewed so far on HIV and identity are focused on the Western context. Evidential comparisons with studies in a sub-Saharan African context may provide additional insights into the consequences of HIV diagnosis on identity construction in everyday life. One strand of literature that could potentially illuminate these consequences is Seeley et al.'s (2012) research on how HIV identity is incorporated into the everyday lives of people living with the condition in Uganda. The study of Seeley et al. is based on the interviews with 34 HIV-positive individuals who had recently tested negative, but believed for several years that they were HIV-positive. These participants comprise a group of people who were categorised as having HIV 'because their partner was living with HIV or had died of AIDS-related illness or because of their own state of health. Therefore, they were not tested at that time and had their first test when the advent of treatment made confirmation of their status an imperative' (Seeley et al. 2016: 332). Seeley et al. (2012) found that, even though a HIV-negative test resulted in the potential loss of their old selves and the assumption of new identities, the infected individuals did not accept their changed status until they joined The AIDS Support Organisation (TASO).

The membership of TASO confirmed their HIV-positive identity and offered a haven from stigma and an abode where they were encouraged to 'live positively with AIDS', and to develop emotional and physical resilience. TASO's membership also offered HIV-positive individuals: acceptance, self-respect, optimism, and openness with others about their HIV status, especially within their own households. Seeley and her colleagues considered that TASO provided a setting for the public management of the new identity and offered people a platform where they undertook biographical work. Such biographical work was crucial to the remoulding of their former self-image as someone living positively with HIV, and a renegotiation of their new-found status of HIV-negative identity.

A further observation of Seeley et al. provided a new perspective on how membership of HIV-positive communities constitutes a part of biographical work for those suffering from a stigmatised condition to manage their new identities in the face of discrimination and exclusion. The constitution of identity with biographical work in the work of Seeley et al. demonstrated how identity is controlled and negotiated through reclamation of the lost self and the creation of a new identity that Freeman (2016) described as 'identity work'. The consideration of the identity work that ensues from the identity challenges caused by HIV diagnosis is what Freeman (2016) explored in his study of 43 older people living with HIV in Malawi.

Freeman found that the social constructions of HIV were that adults over the age of 50 who were living with HIV are 'finished'; that is, that HIV has decimated their productive capabilities and accelerated their decline to a child-like identity that is associated with powerlessness, social exclusion, and dependency on others. HIV-positive individuals accepted HIV diagnosis with the purpose of retaining their social membership and having access to care/treatment. The treatment thus helps in strengthening their bodies to perform physical work for self-sufficiency/familial contribution, the basic requirement of social membership in any society.

Freeman further observed that older adults worked on their identities by asserting adulthood and challenging stigmatised child-like identity, by aligning with a standard adult identity and countering the accusation of being finished and foolish by presenting themselves as being socially and materially productive members of the community. By engaging in identity work and identity control, the participants deployed a series of cognitive and behavioural responses to curtail threats to their identities as 'adults'.

The review of literature on the impact of HIV on the identity of people living with HIV has demonstrated the close relationship between the self and identity, such that the impact of HIV on identity inevitably shapes the sense of the post-diagnostic self and vice versa. The important themes in the literature on the impact of HIV on the self and identity revolve around healthy self, unhealthy self, illness ownership, identity transition and identity work, which revealed that a lot of the research on identity may also be relevant to the post-diagnostic self. The analysis of these themes has further revealed that the onset of HIV has not only generated HIV-related identities, but also affected other identities of the participants, given the socio-cultural contexts that shape the location of the participants. Also, the studies on HIV and identity were oriented towards how HIV identity is incorporated into, or shaped, the post-diagnostic sense of self in both the pre-HAART and HAART eras. Both the sense of the post-diagnostic self and identity of people living with HIV in both epochs are affected by stigmatisation and socio-cultural contexts, such as membership of the HIV community, personal circumstances/issues, and retention of social membership in the pre-HAART and HAART eras.

However, the uncertainty and death anxiety, that shaped the sense of the post-diagnostic self and identity in the pre-HAART era, was absent in the HAART era due to the effectiveness of antiretroviral medications. Furthermore, questions of how identity shapes the sense of the post-diagnostic self of people living with HIV in the Nigerian context, and the impacts of healthwork on the post-diagnostic self of HIV-positive individuals, have been under-studied. This study seeks to address these issues. The exploration of these questions will help to unpack the primacy of the self and identity around the post-diagnostic activities and practices that HIV-positive individuals undertake around their health in everyday life.

Generally, the relevance of the BBC chain has helped to unpack critical issues that are central in understanding the effects of the biographical context in healthwork and HIV management in this chapter. Therefore, using the BBC chain has demonstrated that the daily management of HIV involves biographical temporality, the body, and the self and identity, as the rationale for one aspect of the BBC chain transferring across to the others.

2.5 Conclusion

This chapter has critically reviewed the literature on HIV management vis-à-vis a sociological perspective on chronic illness. Through this perspective, it has been observed that early studies on HIV management revolved around managing the consequences and impact of HIV (as a chronic illness) on the lives and identities of the sufferers who must manage their condition in an everyday context. The substantive number of studies that have been undertaken on HIV management revolved around significant numbers of interesting themes such as adaptation and uncertainty, coping mechanisms, time, self/identity and stigmatisation, even though

HIV differs from other chronic illnesses based on the timing of its detection, disease progression, and the impact of the treatment regimen.

By focusing on healthwork as the basis of HIV management, this chapter has revealed that managing HIV in everyday life goes beyond the narrow conception of adherence articulated in both the biomedical and social science discourses, but rather centres on healthwork—the post-diagnostic activities and practices those sufferers of chronic illness utilise to repair and reconstruct the disrupted biographies and restore the disrupted biography, body, and conception of self (BBC) chain. By redefining and expanding healthwork through the framework of biographical work, this chapter further delves into the discourses on the impact of HIV management on biographical time, body/embodiment, and the conception of self and identity.

Having reviewed the relevant sociological literature in relation to HIV management, it can therefore be concluded that considerable gaps exist in relation to the following questions:

- What are the kinds of practices (healthwork) that people living with HIV undertake around their health and treatment in Nigeria?
- How does the sense of temporality of HIV-positive people become altered by HIV diagnosis, and to what extent is this shaped by healthwork?
- How is the dimension of corporeality of HIV body-in-themself constructed by HIV-positive individuals, and to what extent is this shaped by healthwork?
- How is the post-diagnostic self and identity constructed by HIV-positive individuals, and to what extent are these shaped by healthwork?

  —How does HIV identity shape the sense of post-diagnostic self?

By using Nigeria as a case study to explore these questions, it is necessary to understand how healthwork constitutes HIV management in everyday life of HIV-positive individuals in a non-Western context. In the following chapter, the methodology that was employed to answer these research questions will be discussed.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The data for this analysis comes from the semi-structured interviews conducted with 32 participants in two HIV support groups in Akure, Nigeria. This chapter presents an overview of the research site, method used to obtain data, and other research issues that are instrumental in answering the research questions posed at the end of the previous chapter. The chapter begins by outlining the rationale for using a qualitative approach in section two, coupled with the choice of a semi-structured interview as a data collection tool in section three. The fourth section deals with the ethical considerations of the research. The fifth and sixth sections describe the risk assessment and the form of sampling that was used, the process of selecting the support groups, how the research participants were recruited, and how the participants were interviewed, respectively. The seventh section outlines the role of the researcher in the research process; and the final section presents the analytical approach that was employed to analyse the data from the study.

3.2 Research Design: A Qualitative Study

A research design was determined by the method that the researcher deemed as best suited to answer the research questions. These questions included: What impact does healthwork have on the biographical temporality of HIV-positive individuals? How is corporeality constructed by HIV-positive individuals, and to what extent is this shaped by healthwork? How are the post-diagnostic self and identity constructed by HIV-positive individuals, and to what extent are these shaped by healthwork?

The type of social reality (healthwork and the biographical issues) that was investigated in this study required the use of qualitative methods to investigate individuals' experiences and meaning attached to actions and practices. A qualitative study was used to investigate participants' experience and practices of healthwork because such an approach is best equipped to understand the social reality of experiences. A qualitative study provided a rich account about the healthwork of

HIV-positive individuals and the meaning they attach to their condition and how HIV-positive individuals interpreted their situations. The qualitative method helped to understand the social world from the perspective of HIV-positive individuals and understand the kind of healthwork that is undertaken in the post-diagnostic epoch. In this sense, qualitative research allowed the participants to speak for themselves by giving in-depth answers and enabled them to make sense of and interpret the aspects of their experiences that hold particular significance for them (Ritchie & Lewis 2003).

An additional reason for embarking on a qualitative study stemmed from this study's ontological and epistemological position that the nature of social reality could be known by making reference to the subjective essence of its existence. This research was grounded in interpretivist ontology and constructionist epistemology. The interpretivist ontology posits that social reality is not outside the purview of the participants, but it is actively constructed and constituted by the participants themselves, and such reality (of healthwork) is multiple, subjective, and constructed by the participants in their everyday lives. Constructionist epistemology argues that social reality can be known and understood through the web of interpretations and reinterpretations the participants gave to their experiences. The research findings demonstrated the constitution of different perspectives that were developed through themes (Creswell 2007: 34). The social reality of healthwork can be known through interactive discussion with the participants to 'ask them questions, listen to them and gain access to their account' (Mason 2002: 64). The social constructionist epistemology utilised in this dissertation is reflected in the use of both inductive and deductive approaches. Although it can be argued that the deductive approach is not suited to constructionist epistemology, the deductive approach used here is not about fitting data into theoretically derived concepts, but is useful in breaking down one of the key concepts in this study, which is biography, into three elements—biographical time, the body, and the conception of self/identity. Therefore, each element could be explored inductively within the constructionist paradigm.

Therefore, utilising qualitative research has helped to understand the way in which the social world is understood and produced by actors' lives, behaviour and interactions (Mason 1996; Strauss & Corbin 1990; Marshall & Rossman 1999; Creswell 1998; Vasilachis de Gialdino 2009) through interview-elicited information. In other words, if the social world is that which we occupy and is constructed through social interaction, then there is no basis for the view, talk and opinions of participants to be taken as objective truth, but rather as only constructed truth. In this regard, using a qualitative interview process is relevant in unpacking how users talk about their experience of managing HIV in an everyday context.

In this sense, information elicited by HIV-positive participants should not be seen as a true representation of their experiences, but should be considered as a constructed reflection of their experiences. These constructed experiences were shaped by their current lives, the interview encounter, and as part of a co-constructed process of sense-making/meaning-making between the interviewer and interviewee (Silverman 2011).

These epistemological and ontological positions, however, had profound contributions for many aspects of this study. This included how the qualitative data for this study was collected, how different aspects of the research process were treated as forms of data, and how data collected from this study was analysed. Drawing from the qualitative methodology and the ontological and epistemological frameworks of this research, the following section outlines the choice of a semi-structured interview method of data collection that was used.

3.3 Interview as a method of data collection

The method of data collection that was adopted in this research was a semi-structured interview method. Therefore, the interview method afforded the researcher the opportunity to explore the experiences, opinions and perspectives of people living with HIV who engaged in healthwork, to be elicited through in-depth and detailed conversations. The reasons for choosing a semi-structured interview were the following. First, unlike a structured interview approach, a semi-structured interview enabled the researcher to develop and ask a clear set of pre-arranged, open-ended questions that were derived from the research questions and research themes posed in this study (Evans & Lewis 2017). This study was structured around the implications of healthwork on the three key themes of the BBC chain—biographical time, the body, and the conception of self/identity. These themes were the conceptual frames that a semi-structured interviewing method was oriented towards for further exploration. Therefore, a standardised/fixed wording form of closed questions that is central to a structured interview is not applicable to exploring these themes that were associated with this research. This was because a free-flowing approach gave participants more opportunities to discuss issues which were more relevant to them than some of the issues identified by the researcher under a structured interview (please see the interview topic guide at Appendix 3 for more information).

Second, unlike unstructured interviewing, using a semi-structured interview afforded the interviewer the opportunity and flexibility to modify and tailor the questions to healthwork and the elements of the BBC chain of the participants, together with other issues that arose from the interview context but were not included in the interview guide. With a semi-structured interview, the researcher probed participants' responses for further elucidation on answers provided and evoked a new set of question(s) on the new information obtained. Furthermore, the unsuitability of unstructured interviews in answering this study's research questions hinged on its characteristics. An unstructured interview is a method of understanding participants' behaviour without imposing any prior categorisation, or where questions or the answer categories are predetermined (Minichiello et al. 1990; Punch 1998). Since researchers are not allowed to come into the interview context with themes, 'predefined theoretical framework, and questions about the social realities under investigation' (Zhang & Wildemuth 2006: 5), an unstructured interview is, therefore, not suitable for exploring the research questions that were developed from this research's themes. Since elements or themes of the BBC chain contained preconceived conceptual themes to explore the impact of healthwork, using an unstructured interview method was totally unsuitable because the research questions and themes were already concept-driven where interviews and the coding of data are fitted into the existing researcher's conceptual framework.

The third point was concerned with the epistemological stance of the researcher, who believed that this study required interactive discussion with each participant to gain access to their perspectives. The epistemological implications of the researcher demonstrated that the choice of semi-structured interview would help to generate the data that would be needed to map out the relevant contexts that were brought into focus. This would help in the production of situated knowledge about the BBC chain, healthwork and the experience of antiretroviral medication use.

Generally, using an interview as a research tool (especially a semi-structured type) afforded the researcher the opportunity to talk interactively with people living with HIV, listen to them, gain access to their accounts, and to analyse their construction of healthwork. Therefore, understanding HIV patients' experience of healthwork could be known through interviews as this further helped to interact, conceptualise, verbalise and remember the lay construct of their life world (Mason 1996).

Using a semi-structured interview facilitated the construction and co-production of the contextual knowledge where meaning and understanding were created in the interaction between the researcher and the participants. As an active and reflexive actor, the underlying contextual and situated knowledge shaped the researcher to think through their own role in the research process. It also enabled the researcher in asking HIV patients to talk through specific experiences of healthwork in their daily lives. The elicited contextual responses produced situated knowledge about biography, healthwork, and the experience of antiretroviral therapy through specific dynamics of interaction between the researcher and the participants.

One-to-one interviews were selected due to the stigma and shame associated with HIV/AIDS; this required some sort of confidentiality between the researcher and the participants to be evident. As such, participants would not be comfortable in divulging and providing rich data in a focus group setting because of confidentiality issues. Consequently, one-to-one interviews provided the necessary confidentiality to encourage open discussions between the participants and the researcher. Having chosen an interview as a research tool for this study based on these previously mentioned reasons, the section below will address the ethical issues that arose during the study.

3.4 Ethics

The ethical approval for this research was obtained from Royal Holloway, University of London Research Ethics Committee, and the Ondo State Hospital Management Board. This research also adhered to the codes of practices of the American Sociological Association (ASA), British Sociological Association (BSA) and Social Research Association (SRA) in 2018, 2015 and 2017, respectively. Central to these codes of practices is the protection of human subjects/participants, which is critical to the anonymisation of participants, ensuring informed consent for the participants and maintaining confidentiality, secured data storage and the dissemination of findings. Ethics also included minimising any risk of physical and psychological harm to the participants and the researcher, and how the results of the research could be accessed by the participants. This is discussed in the subsections below.

3.4.1 Informed Consent

This research was conducted at two HIV support groups in Akure, Ondo State (Nigeria). Access to these support groups was facilitated by its Coordinators/Presidents, who acted as the gatekeepers for this research. The gatekeepers spoke about my research (information sheet about what the research was all about, as well as the discussion about the recruitment of participants) as part of the agenda at the monthly meeting of the support groups. The gatekeepers furnished the support group members with this research's information sheet and response forms so that they could make informed decisions about the project.

Having furnished the support groups (through gatekeepers) with the information sheet and response forms, the process of obtaining voluntarily informed consent from the participants in this study was enacted. This process offered the participants the opportunity to make a voluntary, rational, and informed decision to participate. The response form outlined where the participants wanted the interview(s) to be conducted, the day they wanted to be interviewed, and whom to contact for the questions to be asked. Those that returned their response forms to the researcher, or expressed willingness to participate via other means such as email and phone, were further contacted by phone.

The points contained in the information sheet and response form were made clear verbally to those who consented to participate in the study before they were asked to carefully read the consent form. Thus, this enabled the participants to ask any question or to seek clarity on any points they were unsure of. Having agreed to participate in the research (participants), the researcher then arranged the time and place of the interview, and then asked the participants to voluntarily sign the consent form on the day of the interview (please see Appendix 2 for more details on the consent form). The research procedures, as shown on the consent form, demonstrated a good way of conducting research in line with global best practices articulated by Fontana and Frey (2000), Ryen (2004), Shaw (2008), and Silverman (2013).

3.4.2 Anonymity and Confidentiality

Central to the key concern in the information sheet, response form and consent form, were the issues of anonymity and confidentiality. The information sheet fleshed out the purpose of the study and the right of the participants to withdraw from the study without giving any reason. The information sheet also included anonymisation of the participants' details and ensured confidentiality of the information provided, and protection of the information given by participants in accordance with the UK Data Protection Act (2018). The issues of anonymity and confidentiality stemmed from the fact that research into sensitive and stigmatised illnesses like HIV/AIDS fundamentally required an assurance from the researcher that anonymity would be completely maintained. This anonymisation meant that the information provided would remain confidential, otherwise the research participants would not engage in the research for fear of exclusion and stigmatisation. To maintain anonymity, all interviews were recorded using a digital voice recorder, while the privacy of the participants was protected by removing any sign of identity from their transcripts.

In other words, the direct quotations from participants were used in the thesis and for the purpose of disseminating the findings of the project in conference presentations and academic journal articles. These direct quotations were anonymised, using pseudonyms to ensure that all the participants were not identifiable. These pseudonyms were derived by the researcher. Furthermore, references to places or people that could provide a cue to the identity of the participants, or reference to specific places that could identify the participants, were removed from the reporting, which ensured that this information would not appear in the publications.

3.4.3 Storage and access to the data/result of the research

The data obtained from the participants was stored and kept in a password-protected folder on two different computers until the research was completed. The first computer is the researcher's university computer, where the documents were encrypted with the assistance of the university's IT department, and placed in the personal space of the university server that has sole access by the researcher.

The data was stored on the university computer until February 2021, when the intended project was due to finish, and the researcher will no longer have access to the university's computer systems. The second computer is a personal computer with sole access by the researcher, where all the documents were encrypted and placed in a password-protected folder accessible only by the researcher. At the completion of the doctoral project, all data associated with the participants, including contact details, personal information, and interview transcripts, were destroyed.

By signing the aspect of the consent form that is concerned with the duration of data storage, the researcher will keep the participants' data for three years. Since all participants ticked the column for data storage, the permission of participants about how long their data would be kept has been automatically sought, and further details about how they would be informed of the result of the study were verbally expressed prior to the interview, but no agreement was reached on how they would be informed. Finally, the management, storage and dissemination of participants' data would comply fully with the provision of relevant sections of the Data Protection Act (2018).

3.4.4 Research Participant Reimbursement

Participants were reimbursed (£10) for their travel costs to the interview venue, and no further reimbursement was provided for the participants that took part in this research. This ensured that the research was conducted in an ethically sound way in which participants were not induced with money to participate but offered to willingly participate to tell their own stories. Having addressed the ethical issues that may likely affect the integrity of the research process and its findings, what is to follow is the consideration of the risk assessment of the fieldwork.

3.5 Risk Assessment

A preliminary assessment that regarded the potential risks of the research to the participants and researcher was undertaken. The outline of the risks to the participants was communicated to them via the information sheet. The interviews were conducted at a conference room of the Network of People Living with HIV (NEPHWAN) state office in Akure. NEPHWAN is an umbrella body that coordinates all the activities of all HIV support groups in Nigeria to the present day. To minimise physical risk to the researcher, a family member of the researcher was informed about the details of the interview venue and the contact details of the gatekeepers prior to the researcher travelling to undertake the interviews. The family members were also informed via mobile phone when the interviews were concluded. In addition, the coordinators (gatekeepers) of the support groups were present at the interview venue, but were not allowed in the room where the interviews were taking place.

The physical and psychological well-being of the participants was of great concern in this study. HIV-positive individuals belong to a vulnerable group of people because of their susceptibility to emotional injury or harm, especially when asked or reminded about certain aspects of their past lives in connection with how they were infected with HIV (Andersen et al. 2000; Skinner & Mfecane 2004; Ayres et al. 2006). Because of this, the person infected with HIV could reflect on his or her current personal life and future after the diagnosis of HIV, re-evaluate their life values, and feel like a condemned person in society because of the existing negative attitudes (Skinner & Mfecane 2004).

My previous interviews with people living with HIV furnished me with an intensive experience of how to understand HIV-positive individuals as vulnerable people, which included the trigger factors that could reveal the concerns that individuals could present. These trigger factors would include blaming the participants for being infected with HIV, comparing or labelling the participants as HIV patients, and attributing HIV as a disease rather than a condition.

Furthermore, extreme care was undertaken to minimise the potential psychological distress or discomfort to the participants by making it clear prior to the interview that their involvement was optional, and they could withdraw at any time. The participants were also given the opportunity to suspend the interview for a short time or until a later date. During the interview, it was within the statutory rights of the participants to decline or refuse to answer any question or stop the interview at any time. After the interview, the participants had the option to remove their consent for their interview data to be used in the analysis and write-up phase of the project.

Even though interviewing HIV-positive individuals about the experience of healthwork had the potential to cause emotional discomfort to the participants as described earlier, there was no risk of discomfort, distress or inconvenience to the researcher during the interview process. In outlining how potential distress or discomfort could be minimised to the participants in this study, it was made abundantly clear that participants were encouraged to speak to their support group executives and counsellors if they felt they needed extra support following the interview. Having undertaken a thorough risk assessment, what is to follow is the consideration of the fieldwork process where the data was collected in relation to the context, sampling, and how the participants would be interviewed.

3.6 Fieldwork procedure

The data for this study came from two research sites in Akure, a city located in South-Western Nigeria. Akure is a 490/km^2 area and capital city of Ondo State (as shown in Fig. 4.1) and has a population of 570,500 as at the 2011 population estimate (NPC 2014). Despite being the capital city, Akure still maintains some semblance of a separate governance identity with a rich cultural, social, religious and historical heritage.

Fig 3.1: The map of Nigeria showing Ondo State

In a broad sense, the decision to choose Nigeria as a research context and Akure as a research location stemmed from the recent report that Nigeria (due to its population) has the highest rate of HIV/AIDS epidemic in sub-Saharan Africa after South Africa (UNAIDS 2013). The research location (Akure) and sites were selected by the researcher because of convenience, having conducted interviews with people living with HIV in these settings in 2014, which made access through the gatekeepers a much easier process. With Nigeria having a population of 170 million, approximately 3.5 million individuals were HIV-positive (Tocco 2017: 77), while Ondo State (which contains Akure as the capital city) has a prevalence of 4.3 percent of individuals who are HIV-positive (NACA 2015). The research procedure undertaken in this dissertation revolved around sampling, recruitment of participants from support groups, and the collection of data vis-à-vis interviewing of participants.

3.6.1 Sampling

The sample for this research was purposive and strategic (Glaser & Strauss 1967; Bryman 2008) such that it involved selecting a specific group to study based on their relevance to the research questions and the theoretical approach being undertaken towards the research. The sample for this study fulfilled the theoretical and practical needs of the research and, thus, the sampling method was appropriate.

The selection criteria for recruitment to participate in this research was that participants must be HIV-positive individuals who have been taking antiretroviral medications for at least two years. The minimum of two years of antiretroviral medication use was set because the intended period is enough for participants to have undergone meaningful experience in managing their HIV condition. Within two years, participants would have had meaningful experience in relation to the activities that participants undertook to look after their health, such as medical check-ups, CD4 blood testing, meeting doctors' appointments, obtaining new drugs, etc.

These participants were recruited through HIV support groups. The choice of support groups as research sites for this study was purposely selected because of three reasons. First, support groups provide spaces that produce a sense of community and which are free from judgement (Ussher et al. 2006) and are sites where information and experiences are shared (Barbuto et al. 2011). Second, access to participants via support groups is easy, less bureaucratic and less cumbersome, unlike government hospitals in Nigeria where ethical approval for this kind of research seems time-consuming and cumbersome, while lengthy processes are associated with getting ethical approval from government and private hospitals in Nigeria. However, with HIV support groups, the researcher had the opportunity and privilege of interacting and negotiating with the gatekeepers (who formed part of the leadership of the support groups) in a bid to allay fear and confidentiality concerns. Thirdly, HIV support groups are particularly HIV-educated groups because they are more knowledgeable than some of the general population, and their HIV education is informed by experience, daily practices, and an informal network of educational training, counselling, seminars, and group meetings.

In the Nigerian context, HIV support groups sometimes serve as a source of support in the face of stigmatisation, prejudice, and exclusion to members, and serve as a platform for AIDS activism and resistance. The membership of most support groups range from 50 to 300 members. By meeting fortnightly, HIV support groups become places where HIV-positive individuals continue to attend and socialise after their needs have been met (Coreil et al. 2004). The recruitment through support groups helped in gaining access to the participants and facilitated the acquisition of useful data used in this research.

Second, recruitment through support groups allowed participants to speak out freely, as opposed to when recruitment is undertaken through the hospital process. This is because participants' perception about recruitment via the hospital process could be seen as a clever way of accessing information given to the researcher by the hospital management, and thus participants could be unwilling to participate in the interview(s) for that reason. Therefore, recruitment via support groups resolved this perception issue, as the support groups endorsed the research, which increased the sense of legitimacy and allowed the participants to offer valuable information during the interviews.

In Nigeria, HIV support groups were formed at HIV treatment centres where HIV-positive individuals receive treatment. Nevertheless, HIV support groups still maintained their autonomy and independent status, meeting fortnightly and electing their representatives (mostly the coordinator, secretary and financial secretary), who relate and negotiate with the treatment centres on behalf of the group about their treatment plans, health information, and other issues affecting the group. This, however, made it easy for the researcher to approach the representatives of the support groups directly without necessarily gaining access to the potential participants through the hospital where they receive treatment.

Currently, there are about 820 HIV treatment centres (Tocco 2007: 76) that are spread across Nigeria. Since HIV support groups were affiliated with HIV treatment centres, two HIV support groups in two HIV treatment centres in Akure were purposely sampled and selected as the site where this research took place. These two HIV support groups were conveniently selected because of the diversity of the differences in the participants' population in terms of rural and urban dwellers.

3.6.2 The recruitment from support groups

Initially, the researcher had wanted to recruit participants from HIV treatment centres and, thus, contacted the HIV treatment centres in the study's location. It was observed that HIV support groups were formed in the hospital and members were automatically recruited into the group for many reasons. Hospital management informed the author that there were no guarantees to be made that people living with HIV (who receive a free antiretroviral drugs programme through HIV treatment centres) would participate without being contacted through their support groups. In the study location, there were six HIV support groups linked with six HIV treatment centres and they were purposely selected, approached and contacted by the researcher. Only two HIV support groups contacted and informed the researcher about their willingness to participate in the research. The researcher furnished the executive council of these two HIV support groups with an information leaflet and response form through their coordinators (who later acted as gatekeepers).

After a lengthy discussion of the proposed project, the executive council approved the proposed interviews in November 2017 and included the proposed interviews as part of the agenda in the monthly support group meeting held in December 2017. At the December 2017 meeting of the support groups, the proposed interviews were extensively deliberated upon, and approval was granted conditionally. The proposed interview was granted on two conditions: first, the researcher must strictly adhere to the ethical code of conduct stipulated in the information leaflet, response form and consent form that the researcher furnished for consideration; second, the confidential agreement outlining this ethical code of conduct should be signed between the researcher and support group before the interviews commenced in February 2018.

The discussion of the proposed interview at the monthly meeting of the support group helped to provide enough information to the members of the support group, and thus paved the way for the recruitment of participants for this study. A few weeks after the permission to conduct this research interview was granted, the researcher furnished the gatekeepers with an information leaflet and a response form to be circulated to members in January 2018 who attended the meeting of the support group. The gatekeepers asked the members that were interested in this study to contact the researcher directly via phone or return the response forms through the post. However, 45 members contacted the researcher either via phone or by returning their response forms to indicate their participation. The indicated members were then contacted on the phone by the researcher to discuss the study, duration, time, and venue for the interviews and how to return the consent forms. Only 32 members from both support groups returned their consent forms, and they were the participants for this study. For clarity, the first support group is referred to as ‘Support Group 1’ and the second one is referred to as ‘Support Group 2’. The first support group was based in the centre of Akure (urban centre). The membership of the first support group is urban and consists of predominantly middle-class people. The second support group was based on the outskirts of Akure (rural area), and its membership consisted of peasants, famers, petty-traders and under class as shown in Tables 3.1 and 3.2 below. The information elicited from the participants in these two support groups reflected their location/class background and provided rich empirical data for this study.

3.6.3 Sample Characteristics

The tables below show some key details about the sample recruited for this study. The participants were men and women, whose ages ranged between 30 and 58 years. Out of the 32 participants, only 23 were married while the rest were either a widow/widower, divorced, or single. The participants were all heterosexual. The tables further revealed the educational backgrounds and occupational status of the participants.

Table 3.1: Participants' socio-demographic profile

Participant(s) Name	Support Group	Age at the time of Interview	Gender	Marital status	Occupation	Education
Kay	1	44	Male	Married	Artisan	High School Graduate
Oyin	1	38	Female	Married	Trader	High School Graduate
Yemmy	1	47	Female	Married	Trader	Primary/Elementary School Graduate
Ibukun	1	48	Female	Divorced	Trader	High School Graduate
Betty	1	45	Female	Married	Trader	Primary/Elementary School Graduate
Hope	1	35	Female	Married	Trader	High school graduate
Bohun	1	45	Female	Married	Trader	High school graduate
Menty	1	43	Male	Married	Pharmacy Assistant	College/Polytechnic Graduate
Sattu	1	30	Female	Married	Trader	College/Polytechnic Graduate
Segun	1	57	Male	Widowed	HIV counsellor	High school graduate
Praise	1	52	Female	Married	HIV Counsellor	Primary/Elementary school graduate
Sida	1	36	Female	Married	HIV counsellor	High school graduate
Ladun	1	40	Female	Widowed	HIV counsellor	High school graduate
Davis	1	58	Male	Married	Artisan	High school graduate
Moji	1	38	Female	Single	Civil Servant	High school graduate
Adeola	1	59	Female	Widowed	Retiree	Primary/Elementary school graduate
Ade	2	48	Male	Married	Trader	College/Polytechnic

						Graduate
Joy	2	39	Female	Married	HIV counsellor	University graduate
Adetoun	2	58	Female	Widowed	Trader	High school Graduate
Flakky	2	38	Female	Married	Trader	College/Polytechnic Graduate
Bose	2	35	Female	Married	Unemployed	University graduate
Kenny	2	48	Female	Married	Fashion designer	High school Graduate
Bimbo	2	38	Female	Married	Trader	High school Graduate
Johnson	2	57	Male	Married	HIV counsellor	High school Graduate
Funmi	2	34	Female	Married	Unemployed	University graduate
Tossy	2	55	Female	Married	Hairdresser	High school Graduate
Vicky	2	45	Female	Widowed	Trader	High school Graduate
Gbenga	2	58	Male	Divorced	Retiree	High school Graduate
Omooba	2	57	Male	Married	HIV counsellor	University graduate
Mercy	2	41	Female	Widowed	Catering assistant	Primary/Elementary school graduate
Nike	2	39	Female	Married	HIV counsellor	College/Polytechnic Graduate
Lara	2	39	Female	Married	Civil servant	High school graduate

However, Table 3.2 below specifically revealed observations about the current treatment information of the participants and how long the participants have been living with HIV, which is between 3 to 30 years. From the table, it can be revealed that more than 60 percent of the participants used Nevirapine as their main medication, while other medications such as Truvada, Lamivudine, and Zidovudine constituted a significant proportion of highly active antiretroviral (HAART) combination therapy.

Table 3.2: Participants' profile on illness and treatment information

Participant(s) Name	Support Group	Years living with HIV
Kay	1	4
Oyin	1	7
Yemmy	1	12
Ibukun	1	12
Betty	1	11
Hope	1	6
Bohun	1	3
Menty	1	11
Sattu	1	5
Segun	1	13
Praise	1	27
Sida	1	9
Ladun	1	9
Davis	1	11
Moji	1	9
Adeola	1	13
Ade	2	7
Joy	2	12
Adetoun	2	11
Flakky	2	10
Bose	2	10
Kenny	2	12
Bimbo	2	10
Johnson	2	12
Funmi	2	3
Tossy	2	6
Vicky	2	11
Gbenga	2	13
Omooba	2	30
Mercy	2	9
Nike	2	8

Lara	2	6

This sample of participants demonstrated in these tables revealed the unique set of characteristics about the participants who have been living with HIV for at least two years. The tables provided little information about healthwork because most of the participants' data about healthwork were qualitative and voluminous and, as such, cannot be presented here. The next chapter, Chapter Four, is devoted to providing such information. Having provided information about the socio-demographic profile of the participants, the next stage is to extend the discussion about the process in which the data for this research were collected from the HIV support groups in the section to follow.

3.6.4 Conducting Interviews

The interviews were conducted between February and April 2018. The interviews were audio-taped and lasted between 30 and 50 minutes. The participants were interviewed at the conference room of the NEPHWAN state office rather than in a hospital setting. The reason for this was because the conference room provided a sort of private space for the participants to hold our discussions and interviews without the prying eyes of any medical staff. Also, most of the participants' significant others may not have been aware of their HIV status, and as such participants may not have wanted the interview to be held in their own homes. Therefore, the conference room, with its many attributes, provided the best-suited venue for the interviews to be conducted in. The interviews were conducted in English and Yoruba languages, depending on the choice of the participants. The participants who communicated in English or Yoruba languages did so because either of the languages represented the best way for them to express themselves. In this sense, the participants were able to speak eloquently and freely on a wide range of issues in any of the two languages.

The participants were asked questions related to the following: how they were infected, living with HIV, the kind of healthwork they do with their medications, and other questions as contained in the interview topic guide (see Appendix X). The interviews were audio-taped, and the interviews lasted between 30 and 50 minutes. To generate data on the BBC chain and aspects of healthwork that were broader than just medications, the interview topic guide was structured around three key themes of the BBC chain—biographical temporality, the body, and self/identity coupled with a theme on healthwork. The questions related to these themes were asked and further probed into the participants' answers, which were undertaken to generate data on any of these themes. Furthermore, the face-to-face interview provided the researcher with the opportunity to take notes of social cues exhibited by the participants with a view to gaining further information than would be provided by the verbal answers of the participants (Opdenakker 2006). This helped to question and follow up on the previous answers given.

3.7 The role of the researcher in the research process

The practice of reflexivity in qualitative research was particularly significant when the researcher's influence was acknowledged in the data (knowledge) production and analysis. The effect of the researcher's influence in a qualitative interview often shapes the research findings. The ontological and epistemological stance taken by the researcher in this study ensured that participants were treated as active and reflexive agents, whose contribution and participation to the research process was *sine qua non* (Murphy & Dingwall 2001). This was demonstrated in the way in which the researcher used the term 'participants' rather than 'respondents' as this would reduce any power-imbalance in the research process.

Power, as Fairclough (1989) argued, involves constraining and controlling the contributions of non-powerful participants by the powerful participants in the discourse. The use of power in an interview process (especially in a semi-structured interview) involves controlling, constraining, and enforcing one's will, view and interest on others, albeit in a covert or overt form (Wang 2006; Anyan 2013). In this study, the other way in which the power-imbalance between the researcher and participants could be reduced was to follow the practice of allowing the participants to exercise their powers. The participants could do this by exercising their will to discontinue the interview session or be reluctant to respond to the questions posed by the researcher. By using this approach, participants were thus treated in an equal proportion and measure to the researcher.

The utilisation of qualitative research, especially in the context of exploring the experience of living with HIV vis-à-vis healthwork, required the reduction of power-imbalance between the participants and the researcher. This is because face-to-face encounters allow a level playing field where exercise of power is reduced. It therefore requires the researcher to be reflexive throughout the entire research process.

Reflexivity is a form of self-interrogation approach that the researcher employs in scrutinising his/her position in the research process and questioning his/her own knowledge about the research (May 1999). Reflexivity also describes the relevant aspects of the self and position, especially assumptions, biases, expectations, and experiences that shaped the conduct of the research (Greenbank 2003). Fink (2000) articulated seven stages through which the roles of qualitative researchers were embedded in the research process, as follows: thematising, designing, interviewing, transcribing, analysing, verifying, and reporting.

The implications of espousing reflexivity in this chapter were to demonstrate that the researcher would be involved in every aspect of the research process, especially any decisions to be made about how a participant should be given a voice, and whether the context would be relevant to participants' response or not (Fink 2000), and how the data collected would be processed, analysed, and presented. The consequences of reflexivity with respect to this study were that research findings and knowledge production about healthwork were not a stand-alone process or data generated by the participants alone, but co-constructed by the researcher and participants alike. Since reflexivity in qualitative research is tied to the researcher's role and influence in the research processes, such reflexivity often emanates from the identity and background of the researcher, which can shape the research outcomes or affect the integrity of the study.

The socio-demographic characteristics such as culture, gender, race, disability, and sexuality could produce different research outcomes if both the researcher and participants were from the same or different backgrounds in terms of culture, gender, race, disability and sexuality. For instance, in this study, no differences were found in the data from those from a different social background in terms of culture, race, disability, and sexuality. However, one factor that had given shape to the interview context of this research between the researcher and participants was gender-related issues. Gender represents the important factor in this interview context because of the involvement of female participants that were to be interviewed by a male researcher. Central to this gender dynamic were the notions of gender similarity (male-to-male or female-to-female interviewing) and gender differences (male-to-female or female-to-male interviewing) (Williams & Heikes 1993). Due to this gender dynamic, feminist scholars in Women's Studies were of the considerable opinion that female interviewers are more able to access the 'real' experience of women and received feminist responses in interview situations than male interviewers (Oakley 1981; 1998; 1999; Riessman 1987; Huddy et al. 1997; Horn 1997; Hamburg & Johansson 1999; Pini 2005). Similar findings in Men's Studies have demonstrated how qualitative data is shaped by men's performance of gender with male interviewers (Arendall 1997; Schwalbe & Wolkomir 2001; Oliffe & Mroz 2005). The insights in existing literature highlighted two important implications. First, existing studies have focused on how gender dynamics resulted in men interviewing men and women interviewing women, especially in strongly gendered contexts. Second, the consensus in those studies seems to suggest that gender difference in interviewing produced tension that could 'potentially limit expression within the interview and potentially cut short or truncate the dialogue' (Broom et al. 2005: 55). The insights from these studies are leading to a conclusion that gender differences between interviewer and interviewee can produce substantially different research outcomes.

What is missing in these studies is the lack of engagement on possible ways in which interviewers can obtain rich and valuable information despite interviewing participants whose gender differs in the research context and in practice. In addressing this lacuna, this research followed the suggestion of Schwalbe and Wolkomir (2001: 91) that researchers should move beyond the question of 'Who is asking whom?' to 'Who is asking whom about what?' when examining the impact of gender in the interview process. In this research, the question of 'Who is asking whom about what?' would be applicable to both male and female participants, albeit in different ways. For instance, the researcher exhibited more openness when asking male participants about everything that was sensitive to men's healthwork and issues relevant to the study's research questions such as previous relationship and current sexual practices. As for female participants, the researcher remained sympathetic to their cause and condition, and refrained from probing participants' responses into areas that appeared sensitive or distressing for female participants, such as probing into their private sex lives or how they handled post-treatment sexual practices. Having this approach helped in three ways. First, it doused the tension that could arise by asking questions that impinged differently for the female participants. Second, it helped in building a rapport that was leveraged upon in eliciting and obtaining important information from the participants. Third, it helped to mitigate gender effects that often arose when interviewees' responses were developed in relation to interviewers' opinions and orientations within that gendered context. This reflexive stance enabled the researcher to mitigate the challenge of maintaining gender equilibrium during the interview context. Apart from gender, another area that the researcher needed to be reflexive about involved the role of language used in the research process.

3.7.1 Reflections on language in the research processes

The role of language in a qualitative interview required greater reflexivity where the researcher must not only examine his/her own role in the process, but also account for the language in which the research process was undertaken. The effects of language in the research process—interviewing, transcription, translation, analysis, and reporting—may have a noticeable impact on the data that were generated. As the researcher is a native-born Nigerian, speaks Yoruba language and has been taught in English at all education levels, the undertaking of the interviews in two languages (English and Yoruba) might lead to potential loss of meaning between the first and second languages. To minimise this, a localist approach to interviewing (Welch & Piekkari 2006), which prioritises an awareness of the interview as interactional and social in nature, was adopted in this study. The localist approach argues that the production of meaning is localised, and the interview is inherently bound by the social context in which it takes place (ibid: 420), where both participants and the researcher draw upon their shared cultural knowledge to make sense of each other (ibid: 423).

The interview topic guide for this research was designed in English, and the process of generating localised understanding required translating the questions into Yoruba language to elicit important responses during the interview. Since words, terms and concepts can lose their meaning if translated into another language, the translation of questions in the interview topic guide into Yoruba was undertaken to reflect the original meaning of those questions in English, without losing their meaning. This helped to foster a shared cultural understanding between the participants and the researcher, generate localised understanding about healthwork and other issues, and reduce the effects of language on interview data. With the localist approach, interviewing the participants in their native language enables the researcher to follow up on participants' responses and probe such responses through cultural understanding.

Furthermore, the researcher drew on shared cultural understanding, and Yoruba language skills, when transcribing and translating the interview data. This helped to ensure that cultural reality of participants' responses was captured during transcription and translation without losing the original meaning or distorting the accuracy and authenticity of the interview data. During analysis, the translated interview data was organised into codes, sub-themes, and themes that reflected their actual representation of localised understanding in a cultural setting. The researcher analysed the interviewed data into codes, sub-themes, and themes based on shared cultural understanding that ensued between the researcher and the participants. In reporting, the findings derived from the interviews provided insights into the cultural milieu of healthwork and mapped out the localised consequences of healthwork on the biographies of people living with HIV in daily life.

Nevertheless, the languages in which this research was undertaken have shown that language of interviewing could have a noticeable impact on the data that were generated, and this requires reflexivity on the part of the researcher to demonstrate the credibility of the research. Apart from language, another area that the researcher needed to be reflexive about involved the process of translation in the research process.

3.7.2 Reflection on conducting interviews in different languages

The participants' interviews were conducted between February and March 2018 in Akure, Nigeria. Prior to conducting interviews with the participants, my interview question guide was written in English. Although I know that most of the participants would like to express themselves in the local dialect, namely Yoruba, I did not envisage the challenge that I faced in conducting the interview in Yoruba. Despite being fluent in speaking and writing in Yoruba, having to translate the questions in the interview question guide (written in English) into Yoruba was a challenge that I encountered. I went to the interview room without the Yoruba version or translated version of the interview topic guide. In the first interview that was conducted in Yoruba, I struggled to use the exact meaning of a word in Yoruba for English words, because certain words in English have a different meaning in Yoruba language, and I had to quickly think on my feet to get the best possible Yoruba interpretation that captured the exact meaning of the words in English. Despite this initial challenge, I was able to obtain rich data because it was limited to a few questions. After the first interview, I had an hour's break before interviewing the second participant, also in Yoruba language.

In translating those English words into Yoruba, it was not easy on the first day of the interview to translate the full meaning of some terms like self, biography, and the body, without being accompanied with cultural information and meaning that such terms connote in Yoruba language. This means that certain terms like self, biography and the body have different lexical equivalence in both English and Yoruba language. Lexical equivalence means translating from one language to another through natural expression of grammatical and lexical form in the target language (Halverson 1997; Larson 1998; Yinhua 2011). On those occasions where two languages do not offer direct lexical equivalence, some scholars and linguists have suggested that the researcher should strive towards 'obtaining conceptual equivalence without concern for lexical comparability' (Overing 1987; Broadfoot & Osborn 1993; Temple 1997). The conceptual equivalence involves gaining comparability of meanings of the terms/words by the researcher by having a proficient understanding of the language (Yoruba) as well as the 'intimate' knowledge of the culture (Birbili 2000). Therefore, the slippage between the two languages during the interview, together with the researcher's knowledge of the language and the culture of the people under study and the researcher's fluency in the language of the write-up, which is English, helped to gain conceptual equivalence when translating those words in the interview topic guide into Yoruba and reduce the direct impact on the validity of the data collected.

In fact, the short break that I had between the first and second interview afforded me the opportunity to work out the appropriate conceptual equivalence—the exact

Yoruba translation and the cultural meaning for some words in the interview question guide. Having understood the conceptual equivalence of some terms and words inherent in the interview topic guide in Yoruba, it was subsequently easier to follow up a participant’s response and probe it further in Yoruba language. After conducting the third interview, which was the last one for the first day, I had the complete mastery of the Yoruba meaning of the English words in the interview topic guide, and I was able to overcome those challenges in the rest of the interviews with the participants.

3.7.3 Reflections on the translation dilemmas

The process of the translation of the interview data from one language to another required greater reflexivity where the researcher must not only examine his/her own role in the process, but also account for the dilemmas that ensued during the translation process. The essence of translation, especially in qualitative research as Larsson (1998: 235) explained, is to: ‘reproduce as accurately as possible the source text; use the natural form of the target language; and express all aspects of the meaning in a manner that is understandable’. However, achieving these purposes of translation may not be possible in a practical sense, as the context and language of the data to be translated can constitute various dilemmas that often undermine the importance and validity of the translated data. At the translation stage in this research, the researcher translated all the participants’ interviews that were expressed in Yoruba language into English following the rule of conceptual equivalence. Even with conceptual equivalence models, the experience of translating some interview data is often fraught with different issues, or what I regarded as ‘translation dilemmas’, which could have significant impacts or have implications on the data and analysis. Some of these translation dilemmas that I experienced in this research contained the following. The first dilemma presented itself through the fear of losing the original meaning. Certain words could have multiple meanings and, when translated, the original meaning and intention of the narrative could be lost if translated literally. The danger of this is that the narrative of the translator/researcher may not be able to capture the original narrative in the interview data accurately.

For instance, the onset of HIV diagnosis could cause the infected persons to be concerned or engaged in excessive thinking about their situations. The Yoruba words that were expressed by participants for excessive thinking about a new health situation is called *ronu*. If the word *ronu* should be translated into English the same way it was expressed, the original meaning of the word would be lost, and therefore an impact on the data and analysis would be realised. This is because *ronu* could be translated to mean 'being depressed', 'worried', etc., whereas the correct meaning of *ronu* in the context of the participants' narratives would be 'brooding'. Although a term such as 'being worried' can be used for *ronu*, it has a different meaning in Yoruba culture. With the rule of conceptual equivalence that expressed itself in having insider knowledge and mastery of Yoruba language and culture, this enabled the researcher to overcome this first translation dilemma that was encountered. The second dilemma was that certain words/proverbs/ folktales/dialects had no direct translation and the meaning of these terms could be distorted, if translated. The rule of conceptual equivalence enabled the researcher to provide appropriate cultural and literary meaning of these words and terms during the translation.

Generally, the impact of these translation dilemmas could be profound, as it could create opportunities for researcher's bias during the data analysis. To resolve these translation dilemmas and minimise the researcher's bias that could ensue, the following were the steps that I undertook. The first involved my active participation in the interviewing and transcription processes. By interviewing the participants and transcribing the interview data, it enabled me not only to be familiar with the interview data, but to better understand the grammatical structures (of Yoruba) in which the participants expressed themselves, and this gave assistance to the text into English without any alterations to the original meaning. The mastery of these grammatical structures enabled me to map out words (that contained several possible meanings) and their appropriate meanings for the purpose of translation. In fact, the process of translation started from the direct involvement in the transcription of interview data (Twinn 1997; Tsai et al. 2004; Smith 2008). The conversion and translation of data from the Yoruba language to English required the need for conceptual equivalence, which involves not only the grammatical structures of both languages but the cultural meaning of those words in Yoruba, together with the proficiency in both languages, which I possessed, being fluent in both target languages. Therefore, the transcription process afforded me the opportunity to lay bare and uncover the differences in both grammatical structures and helped me to resolve the translated meaning of homonyms/homographs at an early stage of the transcription process.

Second, when transcribing certain words that have several meanings, the English translation of those words (as it was expressed by the participants) was inscribed in brackets beside the original. The reason for this approach was that, during translation, the meaning of those words and the context in which they were expressed could be quickly recollected without having to listen to the audio tape of the participants again, and thus helped to save valuable time. For instance, a word like *Ojo* has more than three meanings in Yoruba language depending on intonation, pronunciation, the context and the meanings to the participants. Several meanings could be assigned to the word, as it can be interpreted as Ojo (name of a person), Ojo (day or time), Ojo (rain), Ojo (name of a town). To avoid misconstruing what the participants intended and expressed, the English translation was written beside the original in bracket form at the time of transcription. This helped me to translate as accurately as possible the original interview data.

The translation of the interview data of a social context required knowledge of the context (Bashiruddin 2013). Since the researcher understood both English and Yoruba languages and how concepts and words in both languages differed in meaning, there was no loss in translation as the researcher's similar cultural orientation with the participants helped him to understand the cultural meanings and interpretation of the narratives, expressed in Yoruba language. The role of the researcher in this context could be regarded as being a 'cultural insider' (Ganga & Scott 2006; Dwyer & Butler 2009), as the knowledge of Yoruba language allowed the researcher to get close to the participants, and the researcher was able to understand the socio-cultural context and meaning of what the participants elicited (Suwankhong & Liamputtong 2015) and translated appropriately without losing its original meaning. The role of a cultural insider also helped to prevent translation and interpretation bias when the data was analysed for this study and ensured that the translated text was accurate, nearer 'the truth', and reflected the meaningfulness of the data reported.

3.8 Data Analysis

This study utilised a thematic method to analyse the interview data obtained from the participants. Thematic analysis was used to analyse the participants' account of biographical temporality, body/corporeality, self/identity. Other accounts analysed by a thematic method included the past, present, and future courses of action associated with pre-HIV diagnosis, HIV diagnosis, and healthwork that had been undertaken in the participants' everyday life, as seen in the account presented in Chapters Four, Five and Six. With a thematic approach, the data was fragmented into small segments and discrete categories for content coding. Thematic analysis assisted in the search for themes that were relevant to fleshing out the kind of healthwork and other biographical issues and was directed towards discovering patterns and the shades of qualitative meaning that emerged from the transcriptions (Amibor & Ogunrotifa 2012). This process provided the opportunity for the researcher to identify themes through careful reading and re-reading of the data (Ezzy & Rice 1999: 258).

The rationale for utilising a thematic method of analysis in this study revolved around two reasons. The first was that it seemed the most suitable method to analyse semi-structured interviews and was utilised to capture participants' data in this study. Second, a thematic analysis was utilised because it helped to explore, from a social constructivist methodological position that this study adopted, the construction and understanding of the core elements of the BBC chain—biographical time, body/corporeality and self/identity, and healthwork of people living with HIV in a Nigerian context—and the experience and significance it had in their everyday lives. Thematic analysis helped to flesh out how the 'reality' of participants' lived experiences was reflected by these constructions, and the social contexts in which these elements of the BBC chain and healthwork were undertaken.

Thematic analysis for this study began immediately after the collection of data from the interviews with the 32 participants. The process of thematic analysing of the interview data involved four stages. The first stage involved organising the transcribed and translated data into texts. The researcher read and re-read all transcribed and translated texts for each participant to become familiar with the text sets. This was valuable for providing insights, considering alternative interpretations and contradictions, and for thoroughness in interrogating the data (Amibor &

Ogunrotifa 2012: 4). In this stage, the researcher cross-checked and verified the audio-taped interview with that of the transcribed text. Through verification, the researcher also cross-checked and verified the non-English transcribed text with that of the translated version to ensure accuracy, reliability, and validity of the text, and this gave impetus to a preliminary reading and interpretation of the texts to facilitate the coding process.

The second stage involved coding and organising patterns of experiences (Amibor & Ogunrotifa 2012). In this stage, the patterns of meaning and experiences that were related to healthwork and the biographical issues of biographical temporality, body/corporeality, self/identity were identified. The benefit of reading the transcribed texts several times was to ensure that all patterns of experiences deemed most meaningful and relevant to the notion of healthwork and biographical temporality, body/corporeality, self/identity were coded and assessed accurately. This process was done meticulously in a bid to ensure that the statements selected to substantiate the emerging sub-themes were as germane as possible, as well as to ascertain that they were coherent with the other excerpts chosen.

The third stage involved searching for sub-themes among codes. In searching for sub-themes, the researcher combined all the already classified patterns/codes together with relevant data extracts, into sub-themes. Following this process, the collated sub-themes were carefully examined to identify broader patterns of meaning that were later developed into themes.

The final stage involved the development of themes from the already collated sub-themes. In searching for themes, the researcher combined all the already classified sub-themes into themes. In this stage, themes and sub-themes were further elaborated on and their relationship clarified by reading and re-reading all the data. Furthermore, themes were constantly checked to ensure that they: portrayed a convincing story of the data; answered the research questions; and ensured that negative or deviant cases were thoroughly examined. By examining the negative/deviant cases, the themes in each of these categories were substantiated through this process, and the researcher remained confident that the understanding of healthwork and the BBC chain had credibility, validity, and grounding in the data (the excerpt from the participants' constructs). This final stage of thematic analysis in this study involved a constant moving back and forward within the entire data set until the endpoint, where the findings articulated in the themes were constructed and disseminated.

Generally, this process of thematic analysis in this study followed an inductive approach (Frith & Gleeson 2004; Braun & Clarke 2006: 84). The inductive approach to thematic analysis was a bottom-up analysis where coding of data and theme development were data-driven, without trying to fit the data into a pre-existing theory/model or the researcher's analytic preconceptions (Braun & Clarke 2006: 84). In doing this, the kind of healthwork and the participants' understanding of biographical temporality, body/corporeality, self/identity were derived inductively from the interview data which had been first coded into sub-themes. The sub-themes were later transformed into themes that captured the understanding of the healthwork that HIV-positive individuals undertook in everyday life and answered other research questions posed by this study.

3.9 Conclusion

In this chapter, qualitative methods have been outlined as the methodological approach that was undertaken for this study. Through this approach, this research was able to explore the meaning of HIV management, and how these meanings were experienced through the healthwork of people living with HIV in everyday life. Understanding these experiences through participants' elicitation in interview interaction was the basis of the methodological approach that was utilised in this chapter. This approach helped to answer the research questions that were identified in the literature review chapter. These research questions were addressed using data collected from interviews with 32 HIV-positive individuals who had been diagnosed with, or were living with, the condition for at least two years prior to the interviews that were undertaken. Using a thematic method of data analysis, the findings of this research were presented in the subsequent four chapters.

CHAPTER FOUR

HEALTHWORK IN NIGERIAN CONTEXT

4.1 Introduction

The previous chapter has laid the methodological foundation upon which the analytical framework for this chapter is built from. This chapter is the first of the chapters that presents the findings from this research study. This chapter explores the lay understanding of healthwork undertaken by HIV-positive individuals in Nigeria. The findings in this chapter have significant implications in better understanding the consequences of healthwork on the biographies of HIV-positive people, which is covered by the overall research question for this study. Furthermore, the findings in the chapter lay the foundation for findings that were presented in subsequent chapters in this thesis.

In this chapter, the findings of the study on healthwork are presented in themes. In existing studies to date, the concept of healthwork is used to describe the kind of activities that HIV-positive people undertake around their health and treatment (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008), following the exploration of everyday experience of HIV management in Canada. Healthwork was articulated to examine other ways through which HIV-positive people manage their condition beyond the established discourse of adherence. Despite this broad definition of healthwork, the corpus of its applicability may be problematic if applied to a non-Canadian context.

This stems from the fact that a concept like healthwork, which was derived and modelled on the experiences of HIV in a Canadian context, may lose its explanatory power when applied in other contexts especially in sub-Saharan Africa. Exporting the concept of healthwork to non-Canadian contexts requires some thought as to the universal suitability of the concept because of the variances in the social and cultural understanding of health and illness in Nigerian society. Even though the concept may share cross-cultural acceptance, certain components of the concept may not translate well in the Nigerian context. The practice of healthwork is made possible by the free antiretroviral therapy (ART) programme in the Nigerian context. The enrolment of people living with HIV in Nigeria into a free ART programme provided by the state and their continuous participation requires a set of rules and obligation on the part of the users (people living with HIV). Free ART programme, as an expression of governmentality, whilst administered by the state through healthcare organisations, is not coercively undertaken to ensure absolute compliance, even when compliance is the overall objective. The Nigerian state used a free ART programme to monitor the population health of people living with HIV (Tocco 2017) and ensure subtle compliance through self-governance.

Through Free ART programme which governmentality produces, the participants are allowed to engage in responsible self-government that prioritises the disciplining of individual bodies and the enactment of an ethical self-care regime, with a view to maintaining their health. This is what technologies-of-the-self entails, where the participants engage in the governance or discipline of their bodies through ethics of self-care that are primarily personal. Analysing healthwork through the framework of governmentality and technologies-of-the-self require understanding the practices of healthwork that HIV-positive individuals undertake in their everyday lives. In this chapter, I therefore discuss these practices of healthwork as the basis of HIV management in relation to the Nigerian setting, followed by the discussion of the significance of the findings considering previous research on the concept.

4.2 Healthwork in Nigerian context

One of the criticisms that can be levelled against Mykhalovskiy and McCoy’s (2002) conception of healthwork is the failure to articulate the timing of healthwork. The question of when to start engaging in healthwork by chronically ill or people living with HIV was obscured in the works of Mykhalovskiy and his colleagues (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008). In this thesis, healthwork starts following HIV diagnosis. In line with the articulation of Mykhalovskiy and his colleagues’, healthwork in Nigerian context is seen as the kind of practices undertaken around health to support treatment. As previously stated, the practices of healthwork are not free from governmentality and the technology of the self, as some of these practices involve individual responsibility and disciplining of the HIV bodies, by conforming to the rules and conditions for continuous participation in free ART programmes. HIV-positive people in Nigeria utilise a wide range of practices to respond to their HIV diagnosis and minimise a deterioration in their health. These practices which include *spirituality*, *counselling, testing, concealment, adherence, dieting, support group participation and Internet use* are the components of healthwork in Nigerian context and constitute the mundane way of managing HIV in everyday life. The section that follows will now focus on how participants discussed each of these practices in turn.

4.2.1 ***Spirituality***

Spirituality is the belief that human affairs (or the physical realm) are being controlled by ‘spiritual beings’ and connecting with spiritual beings are beneficial to human purpose (George et al. 2000; Waaijman 2007). With the highest number of churches, mosques, and traditional shrines on earth, Nigerians have been adjudged as one of the most spiritual and religious people in the world (Ugwu & Ugwu 2013).

Spirituality is embedded in everyday life of Nigerians, in respect to how they cope with many of life’s challenges such as job loss, disaster, insecurity, and health issues; and when confronted with problems/difficult circumstances they considered as beyond their control or defy human solution (Fatiregun et al. 2009; Onifade et al. 2013). Since HIV does not have a cure, the disease is considered as defying human solution and HIV-positive people in Nigeria resorted to spirituality (such as praying and visiting religious centres) as a way of responding to HIV diagnosis. The narrative of Joy, (a 39-year-old-woman, living with HIV for 12 years), illustrates how spirituality is a form of a readily available resource for HIV-positive people in Nigeria to advance their lay knowledge about how to deal with their newly found health situation:

> When I got to know my HIV positive status, I said God forbids it. The test result sheet, I shredded it and trashed it into a street bin. I rejected it. Initially I denied it. At this denial stage, I refused to take steps. The only step that I took was more spiritual. I was praying, believing God that I will be healed. When I later broke down and sickness took its toll on me, and I was looking at death coming, I took the result to somebody that I knew in my ministry [church] at that time, that was running an NGO (Youth for Christ), and I explained the situation to the person. It was through that organisation that I started receiving treatment in [a city].

Joy’s rejection of her HIV positive status was activated by her lay understanding of ‘HIV as evil’ that has no God imprimatur. The subsequent HIV denialism was fuelled by the belief that the solution to human suffering and condition especially HIV is beyond human efforts, and can only be found through spiritual intervention, following intensive prayer. The recourse to church—a key site of spirituality—following the outset of opportunistic infections, demonstrated the fact that spirituality may be the first point of healthwork—where healing and a possible solution to HIV may be found. Even when such intervention did not emerge from the church, the ministry's linked NGO became the fulcrum where pharmaceutical intervention to HIV diagnosis was later found. Spirituality, as demonstrated from Joy's account, is closely associated with religious beliefs.

The practice of spirituality is in abundant supply in Nigerian society, as it is derived from three dominant religions—Christianity, Islam, and traditional African religion (Hackett 1988; Ibrahim 1991; Smith 2004). Each of these religions are the resources from which lay people derive their knowledge of spirituality. Spirituality therefore becomes a lay resource for participants like Ibukun to respond to her HIV diagnosis. When Ibukun (a 48-year-old woman, living with HIV for 12 years) knew about her HIV positive status, she reported the following:

> I nearly committed suicide that day that I was told of my HIV status because I would prefer to die than to have HIV. I was pregnant at the time, and I needed to visit the hospital. After a few days of thinking about HIV, I later saw it [HIV] as a positive way for me to impact positively into the lives of others. I think God knows why I was infected with HIV, maybe to humble me in a certain way, or he [God] wanted me to change part of my lifestyle or maybe because God knew that there would be some people I had to meet in my life journey. Since I realised this, I moved on with my life.

The acceptance of HIV positivity is facilitated by the participant's incursion into spirituality as a means of making meaning out of HIV diagnosis. In Ibukun's narrative, accepting HIV as God's will enables the participant to eschew the thought of suicide, depression and anxiety that are associated with being infected with HIV. Spirituality, as an important form of healthwork, is about creating a way of accepting the reality of HIV positivity and to be able to live with the condition, as Ibukun's account indicated. The practice of spirituality constituted the balancing act of creating something positive out of their HIV conditions or the acceptance of HIV diagnosis as something positive, suitable, or designed to achieve a particular purpose in human life. If spirituality is the rationalisation of the HIV diagnosis as acceptable for Ibukun, spirituality for Yemmy (a 47-year-old-woman, living with HIV for 12 years), is about invocation of spiritual rhetoric into the efficacy of antiretroviral medications:

> When I was told about the result of my HIV test, I was devastated and began to cry. The counsellors at the hospital told me that having HIV is not the end of the world. I thought they [counsellors] are deceiving me that I won't die, even when it is being announced daily on television and radio about the deaths of HIV-positive people. But when I went to the hospital and saw lots of people living with HIV for a long period, then I changed my mind. When I got to the church the following day, I was praying that God should allow the drugs that I would be given to fit perfectly with my condition.

Spirituality is deeply ingrained in Yemmy's narrative, which manifested through an appeal to the supernatural being (God) for the antiretroviral medications that would be given to her to be effective. The readiness to participate in healthwork is underpinned by the participant's lay knowledge that medications on its own cannot effectively suppress HIV unless spirituality is invoked into its usage. Generally, spirituality constitutes healthwork because the participants utilised their lay understanding to invoke the ingrained spiritual knowledge in creating meaning out of their HIV positivity, as a leeway for the acceptance of HIV diagnosis and desire to manage their conditions effectively.

Since health maintenance and staying healthy is the primary objective of free ART programmes in Nigeria, resorting to spirituality is a way in which the participants maintain their health in social life. Resorting to spirituality is a sort of ethical self-care regime that demonstrates the interconnectedness in participants' accounts between spirituality (praying to God for the medications to be effective) and practice (such as medication taking) that are traditionally thought to constitute healthwork. Therefore, the religious nature of the Nigerian context enables this sense of spirituality to be forged as the starting point of responding to HIV diagnosis.

4.2.2 Counselling

Counselling involves provision of professional advice, guidance, and information, usually from the counsellor in resolving the personal problems of the client (Feltham 1995). In a HIV context, counselling is usually offered by HIV counsellors to clients and family members of those that are affected by the virus. HIV counsellors in Nigeria provide advice and health/medical information on how to manage HIV conditions and prevent the spread of HIV (Bello et al. 2011).

As part of the free and universal antiretroviral therapy programme in Nigeria, HIV counselling is usually free at the point of service at HIV clinics or hospitals that are enrolled under the ART programme. Counselling is the gateway to governmentality in the Nigerian context because it is a means of social control that is exercised by healthcare professionals through subtler means, with a view to producing self-regulating subjects or individuals that modify behaviours. The enrolment into ART programmes is impossible without counselling, and continuous participation in the ART programmes depends on counselling. Due to its centrality to ART programmes, attending counselling sessions is compulsory and obligatory to the participants, and thus constitutes a pathway to producing a kind of subjectification required for participation and continuous participation in ART programmes following enrolment.

Due to its free and easy accessibility, people living with HIV considered counselling as an opportunity to leverage on the professional information and knowledge of the HIV counsellor to increase their lay knowledge about prevention, treatment, and post-treatment care and support. Counselling enabled Sattu (a 30-year-old-woman, who has been living with HIV for 5 years) to update her lay knowledge as part of the responses to HIV diagnosis:

> When I went for counselling, I was advised not to brood about my condition. I was advised on what to do to keep me fit and healthy. From my own understanding of HIV, it is not HIV that kills but unnecessary brooding about HIV and the condition one finds him/herself.

The participant went into the counselling encounter with their lay understanding, but such encounter becomes not only a pathway to tap into the counsellor's knowledge on aetiology, treatment, and management of HIV condition but to become a subject of governmentality on measures to undertake to become healthy. The participant brooded and became dejected about their HIV diagnosis because of their lay understanding that HIV is a fatal illness with no curative outcome, when another narrative exists that can bring hope. Counselling therefore enables them to challenge previously held beliefs about HIV; and provides positive orientations about their life in relation to their new condition, with a view to challenging possibly negative reaction to HIV diagnosis that could trigger anxiety, brooding, depression, and even suicide. The counselling further reinforced the lay understanding of the participants, especially Bimbo about the post-treatment eventualities that may ensue following the use of antiretroviral medications. Attending counselling enabled Bimbo (a 38-year-old-woman, who has been living with HIV for 10 years) to know how to minimise the effects of the efficacy of medical treatment on her health:

> When I was given the drugs, I was told by the counsellor that it may have side effects for the first time, but if I persist in using the drug, my body will become normal after some time.

Counselling provides a space where governmentality associated with the use of antiretroviral therapy is exercised by healthcare professionals/counsellors. In Bimbo's case, HIV counselling becomes the resource for the participants to understand how their medications work and what side effects are attached to their drugs. The persuasive nature of counselling for Bimbo will produce a willing subject that was swayed by less coercive undertaking and ensure subtle compliance. Without doubt, understanding side effects even before embarking on medication-taking practice, provides the participants a kind of expectation of what to encounter in managing their health outcomes. Subsequently, counselling has different goals and meanings to the participants. To Flakky (a 38-year-old woman who has been living with HIV for 10 years), counselling afforded her the opportunity to avoid HIV re-infection through unprotected sex:

> Before being given the drugs, they counselled me on how to use my drugs, what to eat and what not to eat; they counselled me to abstain from unprotected sex that is all.

Counselling is initiated to produce self-regulating subjects or individuals who can modify their behaviours and selves. The purpose of governmentality is to produce healthy individuals, who would comply with a set of given rules, as demonstrated in Flakky's case. To be healthy, Flakky and other participants who share similar goals, had to abstain from unprotected sex that can undermine the efficacy of their treatment following the counselling they received. Abstaining from unprotected sex is part of the given rules that help to reproduce a particular behaviour under a prevailing social circumstance. This purpose of governmentality is also applicable in Mercy's case (Mercy (a 41-year-old woman, who has been living with HIV for 9 years), where counselling has enabled her to abstain from taking alcohol and local herbs that could compromise her treatment:

> When I was given the drugs, I was advised and counselled not to smoke, drink alcohol, and take local herbs with the drugs because it undermines the efficacy of the drugs. That is all that I can remember about the information I was told then.

The post-treatment counselling is always required before drug refillment can take place in Nigerian context. It is a space through which the participants are monitored to ensure their obligations to be healthy. The counsellor's knowledge was transferred through medical encounters and served as a resource for the participants especially in the case of Mercy, who benefited from useful information about how smoking, alcohol use, and use of alternative medicines can be injurious to her health and treatment outcomes. In contrast to Mercy's perspective, counselling seeks to instil disciplinary practices to Mercy and other participants, by producing subjects/individuals that can undertake responsible self-government of their bodies. To engage in responsible self-government involves abstinence from smoking, alcohol use and other products that can compromise the objective of achieving a healthy body.

Unlike alternative medications that can interfere with the efficacy of antiretroviral medications, alcohol does not interfere with the efficacy of antiretroviral medications except when it is taken excessively, but alcohol use can make people living with HIV forget to take their medications. Smoking is bad for respiratory conditions which HIV infection may reduce the ability to combat, and many HIV-positive individuals may not know the true extent of the link between HIV and cancer. Scientific evidence shows that smoking causes lung cancer (Hecht 1999; 2002; Islami et al. 2015).

In this sense, if an HIV-positive individual gets an opportunistic infection of the lung through smoking, then it becomes more difficult to recover for a smoker than for a non-smoker. The participants' accounts here depict that one of the ways in which HIV-positive people are lay experts, is 'by virtue of having experience' (Prior 2003: 53) through counselling but their demonstration of being experts would come through them passing on that knowledge to others, for instance in support groups. Counselling therefore has two faces: it is thus the acquisition of lay knowledge on one side, and it is the subjectification of governmentality on the other hand.

Generally, counselling constitutes a form of healthwork in the Nigerian context because it is part of practices that participants undertook to support their treatment. Even though it is mandatory, counselling has two faces in this study: the first is that participants considered talking to counsellors as part of responding to HIV diagnosis, and a rational way of upgrading their lay knowledge about how best to manage their conditions in a post-diagnostic epoch. The second is that, by upgrading their lay knowledge through counselling, the participants are subtly controlled by healthcare professionals to regulate and discipline themselves and modify their behaviours.

4.2.3 Testing

Testing is an evidential mechanism utilised to verify and entrench participants' compliance under the ART programmes. In this sense, testing is utilized at the participants' level to police the obligations of the beneficiaries of the ART programmes (that is, people living with HIV) to understand the compliance with their obligations and produce obedient order. Unlike counselling, the professional knowledge that underpins HIV testing extends beyond the competence of HIV counsellors to laboratory scientists, nurses, and doctors. As part of professional specialisation, HIV testing is undertaken by laboratory scientists, but the test results are interpreted by HIV counsellors, doctors, nurses to HIV-positive people in lay terms. The incorporation of this professional knowledge into a lay understanding for HIV-positive people hinges on how patients respond to professional interpretations of the test results. The participants considered testing as part of understanding the progression of their treatment in terms of CD_4 count and viral load test. In the Nigerian context, testing contains two facets—pre-treatment and post-treatment testing—both are required for HIV-positive people. HIV-positive people undertake pre-treatment testing, prior to the commencement of HIV treatment. Tossy is a 45-year-old woman who has been living with HIV for the past six years. She was pregnant when she was diagnosed with the virus:

> When I was diagnosed with HIV, I was 7 months pregnant and the nurse said because of my pregnancy, I was given Septrin, and I was told that antiretroviral drugs will be given to me when the state of my condition will be better known after childbirth. I was told that normally I should have been made to undergo a CD_4 count to know my immunity status and the level of virus in my bloodstream but because of the pregnancy I was given Septrin that day and I started taking the drug that day. When I was given the appointment, I was told that if a CD_4 count test result is 350 there will be no need to start

> taking antiretroviral drugs (ARV), but if the CD_4 count is less than 350, I will be made to start taking ARV because I will continue taking the drug after giving birth. But when the result was given out, my CD_4 count was 340 and they gave me ARV and said that after giving birth I will continue taking the medication.

Testing is one of the key mechanisms of governmentality, as it constitutes a pathway for participants' enrolment into the ART programmes. Following HIV diagnosis, testing is initiated to know when the treatment could commence and when the affected individuals can commence the process of self-governance of their health in post-treatment epoch. The participants interpreted testing as part of healthwork because it enables HIV-positive people to understand how their treatments are connected to their immune system and the extent of the virus in their bloodstream. The use of expert language like CD_4 count revealed the extent to which the participant had updated her lay knowledge about when to start antiretroviral treatment, the condition for such treatment to commence, and what it means to have less than a 350 threshold of a CD_4 count. However, both a CD_4 count, and viral load test are technical and professional language that are translated into lay peoples' terms or everyday language concerning the immunity status and extent of the virus in the body.

Following the use of recommended medications, HIV-positive people participate in post-treatment testing (or follow-up testing) for the purpose of examining and reviewing the efficacy of the medications on the illness. Testing is an evidential mechanism that governmentality utilises to monitor the health progress of the participants, and to gauge the level of their compliance with their obligations. In this regard, the result of post-treatment testing is used to decipher whether non-adherence, reinfection, or drug resistance have undermined the current regimens of the participants to produce healthy subjects. Hope (a 35-year-old-woman, who has been living with the HIV for six years), gave a thematic account of what post-treatment testing encompasses for her:

> Since I gave birth, I have been receiving medications, and I used to go to the hospital every 6 months to undergo a CD_4 count test like I said earlier. When I started taking ARVs my CD_4 count was 348, but since I have been using the drugs, my CD_4 count has never dropped below 500. Sometimes, it can be 500 or 800 but if I had malaria, it may drop to 600. I even undergo viral load tests,

> my viral load was 225 when I started taking ARV, but the last result shows 20, which means that the virus was undetectable in my blood.

As recipients of free antiretroviral therapy programmes in Nigeria, HIV-positive people are mandated to undertake post-treatment testing every six months at the clinic where they receive medications if they want to continue to receive free medications. As pharmaceutical citizens who access free ART from the state, testing is used to understand how effective the self-governance regime is to produce healthy bodies. Nevertheless, the participants used to undertake a CD_4 count and viral load tests every six months because the post-treatment testing was regarded as the resource to monitor the progress of their health in terms of the efficacy of the medications on their immunity status. The mandatory dimension of this post-treatment testing in every six months, constitutes the deepest disposition of governmentality.

In Hope's account, the reduction in a viral load test to 20 means the amount of HIV in the blood has reduced to an undetectable level. The increase in her CD_4 count from 348 to 800 indicates that the participant's immunity has increased to a level that will help to prevent infections and illnesses. Because of the free nature of post treatment testing in Nigeria, the account of the participants demonstrates that HIV-positive people considered HIV testing (CD_4 count and viral load tests) in every six months as a form of healthwork. This is not only due to its centrality in monitoring of their immunity statuses and viral progressions, but also the participants' desire to achieve a reduction in viral loads and increment in their CD_4 count (Langford et al. 2007). The participants therefore considered effective use of medications/adherence, which is discussed in the following section, as the yardstick for attaining these high immunity statuses and lower viral progressions.

4.2.4 Adherence

Adherence is used as part of medical expert language that emphasises patient's compliance with treatment regimen as a matter of individual responsibility to a healthy life (Trostle 1988; Hunt et al. 1989; Donovan & Blake 1992). Adherence requires everyday routinisation of antiretroviral medication-taking at specified times, and compliance with recommended dosages. Adherence underscores the wider issue of self-governance, which exists in relation to HIV prevention and achieving a healthy body and fosters the interconnection between governmentality and technologies-of-the-self. Adherence is the expression of individualised and autonomous self, created by obligations that were defined by individual responsibility and self-governance.

As a professional language with useful information that participants appropriate in a medical encounter, adherence is also understood and interpreted differently by the participants, as it has different connotations in a lay understanding for HIV-positive people due to a cultural understanding of HIV and the social reality of living with HIV in Nigeria. HIV-positive people in the Nigerian context interpreted adherence differently from that of health professionals and undertook adherence as part of their healthwork for two reasons: *fear of opportunistic infections* and *fear of second-line therapy*—that were discussed in the following sections.

4.2.4.1 Fear of opportunistic infections

Lay people learn through experience (Wilson & Meyers 2001). As peoples' experiences constitute part of their lay knowledge, the experience of opportunistic infections constitutes part of the lay understanding of HIV-positive people. When someone living with HIV has a weakened immune system, they are at risk of 'opportunistic infections'—which is when infections occur due to a weakened immune system. The participants do not just follow health professionals' recommendations just because of the need to comply, but due to the fear of opportunistic infections.

> **Joy:** I stopped taking the medications for two months and I was almost dying. So, I just know what I need to take and not that I'm compelled to. It is not a compulsion; I just need to take it for me to live my life and fulfil my days on earth.

The previous experience of opportunistic infections of the participants added to their lay understanding of what it means to be living with HIV. From the account of Joy, HIV-positive people might have previously experienced HIV opportunistic infections and may not want to experience opportunistic infections and illnesses again. Therefore, the fear of opportunistic infections, acted or formed the basis for their adherence to their treatment regimen. In this sense, HIV-positive people engaged in adherence not because of the need for patients' compliance to doctor's instruction, but due to the fear of opportunistic infections. However, the fear of opportunistic infections is the expression and reflection of governmentality, where the desire and obligation to achieve the overall aim of healthy bodies remain paramount to the participants.

4.2.4.2 Fear of second-line therapy

In an illness context, second-line therapy is usually given when initial treatment (first-line therapy) stops working or does not work effectively enough (Walker & Pope 2012). First-line therapy may stop working when the virus (HIV) develops resistance to the medications to suppress it and it continues to multiply. The biomedical stance is that non-adherence to antiretroviral drugs will undermine the efficacy of first-line therapy and thus, cause the patients to be transferred to second-line therapy (Paton et al. 2014; Parikh & Mellors 2016) and this makes adherence crucial. With adherence, the participants become active subjects, whose goals are oriented towards maintenance of first-line therapy that underscores the basis of healthy bodies. The fear of second-line therapy connotes the maintenance of first-line therapy and avoidance of second-line therapeutic regimes that are disruptive to their health and social circumstances.

The account of Ade (a 48-year-old man who has been living with HIV for seven years), demonstrates the fear of second-line therapy as the reason for adherence to HIV treatment:

> You know when they gave me the drugs, I was told to use it at a chosen time regularly and using it at that regular time is good for my health. Without following that instruction, it is very dangerous and can cause bodily harm. I was told that if one misses his/her medication regularly, it could lead the person to be switched to second-line therapy and if it leads to any of these, it means the person’s condition is gradually sliding towards a situation where there will be no therapy and will progress quickly to full blown AIDS. It is because of this reason that I stick to the time I choose to take the drugs so that I will not slide away from first-line therapy that I am currently taking.

The participants’ desire to avoid second-line therapy as a basis of adherence to first-line therapy is the expressivity of technologies-of-the-self in daily management of HIV. From the participants’ account, one of the reasons why HIV-positive people adhere to their medications and other instructions is the fear of being transferred to second-line therapy. The expert knowledge on first and second-line therapy constitutes a tool for HIV-positive people to update their lay understanding about adherence and become the basis for the fulfilment of their obligations under the ART programmes. Another participant, Omooba (a 57-year-old-man who has been living with HIV for 30 years), gave an interesting account of what adherence means as a form of healthwork:

> I was advised that the moment I start with first line therapy and if I miss taking the medication, I can develop viral resistance to the first line therapy that may render the drugs ineffective in suppressing the virus. Then the person will be transferred to the second-line therapy, and if the person misses the drugs or does not use it, then if the virus develops resistance to second line therapy, then there is no remedy again as the third-line therapy is not available in Nigeria and the person condition will quickly progress into full blown AIDS. The second-line therapy is a big dose of drugs and those who use it usually experience severe side effects.

The onus of governmentality facilitated by the healthcare professionals/experts became translated into effective technologies-of-the-self, that was expressed through adherence to first-line therapy. The technical/professional language about the effectiveness of first-line therapy, the complex nature of second-line regimen and the lack of availability of third-line therapy in Nigeria are part of what participants acquired to widen their lay knowledge on adherence to HIV treatment. The lay understanding of the participants was enhanced by the following: non-adherence to their treatment could render their first-line therapy ineffective; and complex regimen/strict conditions and severe side effects associated with second-line therapy formed the basis of adherence to first-line therapy.

The participants' accounts demonstrated an understanding that viral resistance is very unlikely to develop if adherence is followed. Therefore, HIV-positive people will do their utmost to avoid taking second-line therapy, vis-à-vis adherence to their first-line treatment, due to their lay knowledge of the consequences of viral resistance to second-line therapy. The adherence to second-line therapy for many participants stemmed from the lay awareness of the unavailability of third-line therapy in Nigeria, in case of treatment failure, unlike those on first-line therapy.

Generally, adherence as a professional language constitutes healthwork to the participants because it reinforces the lay understanding of HIV-positive people that adherence to antiretroviral therapy is the requisite tool for the maintenance of first-line therapy, and prevention of HIV-related opportunistic infections. Therefore, adherence in HIV context is a laypersons' way of thinking about their health and engaging in a conscious effort towards protecting and improving the health and well-being of HIV-positive people who see adherence as the key to managing their condition. The participants' accounts have revealed that adherence is the basis of the intersection of governmentality and technologies-of-the-self in HIV management. As governmentality and technologies-of-the-self require individual responsibility under a set of rules to produce healthy subjects, adherence is an expressivity of self-governance through which the participants demonstrated their sense of obligations to the pharmaceutical citizenship that was offered through the state ART programmes.

Therefore, the fear of opportunistic infections and fear of second-line therapy are the expression and reflection of governmentality, in which the desire to comply with the obligations of healthy bodies associated with state ART programmes assumed a greater importance and priority. Under state ART programmes, adherence is therefore part of obligations required by the participants, but such obligations cannot occur without the technologies-of-the-self.

4.2.5 Concealment

Most studies on HIV disclosure emphasised the importance of disclosure to sexual partners and spouses as a way of reducing viral transmission, preventing sexual risk behaviour and reducing the stigma associated with having HIV (Miller & Rubin 2007; King et al. 2008; Ssali et. al. 2010). Concealment is about disciplining of one's body by refraining to disclose HIV positive status to others, with a view to stay health and avoid stigmatisation and discrimination that can undermine the health of the participants. Therefore, concealment is an enactment of an ethical self-care regime, that is primarily personal.

The discrimination associated with HIV or HIV-related illnesses in Nigeria made people living with HIV to conceal their HIV positive status (Reis et al. 2005). Discrimination against people living with HIV is rife across all strata of Nigerian society (Reis et al. 2005; Monjok et al. 2009). Therefore, people living with HIV maintained secrecy around their health. In the Nigerian context, concealment is a form of healthwork: a way in which HIV-positive people look after their health and live positively with HIV in everyday life. From the account of the participants, HIV-positive people conceal their condition from both significant others and the public. The account of one of the participants—Bimbo (a 38-year-old woman, living with HIV for 10 years), demonstrates the constitutionality of concealment as a form of healthwork:

> To be honest with you, my mom knew about it and my siblings. Except those people, nobody knows because if I announce my status, people will isolate themselves from me.

The participant disclosed her HIV status to her significant others but decided to conceal it from her wider network of contacts. The consequences of HIV disclosure to the general public could result in being shunned, rejected and ostracised by friendship networks, peer groups, religious organisations and other sites of social grouping where they may experience harassment, threat of violence, public restrictions and sanctions (Busza 1999; Letamo 2004). The implication of partial disclosure means that only the significant others of Bimbo are aware about her HIV condition, but in the case of Moji (a 38-year-old woman, living with HIV for nine years), disclosure of her HIV positive status is forbidden for both significant others and the general public:

> I don't tell my husband because he is talkative, who will announce it to everybody in the town. I keep my medications away from my husband. If I want to take my drugs, I will take them outside the house. Other people cannot know about my HIV condition. People around me sometimes see me taking my medications and I told them that I'm taking paracetamol to treat pain and fever.

The participants concealed their HIV positivity from their husbands and family members due to the fear of marginalisation and social exclusion, which may prevent them from 'participating in the lives of their communities and limit their access to critical social and economic resources' (Izugbara & Wekesa 2011: 874). There is a broader relationship between concealment and stigma in the Nigerian context. As a form of healthwork, concealment facilitated by the ease with which medications can be concealed or the true nature of the medication being taken can be concealed. This denotes disciplining of individual bodies through the enactment of an ethical self-care regime that helped the participants to live peacefully and positively with their conditions by averting to apathy, loneliness, despair, and a decrease in their self-esteem (which resulted from marginalisation and discrimination) that could have worsen their health and well-being.

4.2.6 Dieting

Dieting is the expressivity of disciplined bodies through the enactment of an ethical self-care regime that technologies-of-the-self fosters. As a form of self-regulation, dieting may not always be overseen by clinicians but requires regulated and routinised practice of eating food to maintain, increase or decrease body weight, or in the treatment and prevention of illness such as diabetes and as a way to improve health (Mallyon et al. 2010). Dieting is central to HIV management in the Nigerian context, as HIV-positive people in this study are framing dieting as the solution to the problem of a low CD_4 count (or low immunity in lay terms). Through dieting, increasing a CD_4 count (immunity) becomes the contested arena where healthwork is to be undertaken through disciplined actions. As a mechanism of technologies-of-the-self, dieting is the technique that participants fashion out to deal with their bodies and transform it to a certain healthy state to produce desirable medical outcomes.

The account of Nike (a 39 years-old-woman, living with HIV for eight years) demonstrated how dietary management is central to the healthwork of people living with HIV in Nigeria:

> I eat good food with a balanced diet. I eat fruit and foods that contain protein. I think eating those foods will boost my immunity. That is all.

HIV becomes an interruption that challenges previous dieting routines and forces HIV-positive people to create new understandings, meanings, and frames of reference (Charmaz 1997; Montez & Karner 2005) about managing their condition. The diet regimen of fruits, vegetables, and protein were utilised by the participants on an individualised and self-managed basis to undertake lifestyle changes on a continual basis. Dieting is a disciplinary practice utilised as part of individual responsibility to produce subjects that prioritise the disciplining of individual bodies to produce particular outcomes in a self-care regime. With the imprimatur of healthcare professionals, dieting is the mediation and products of governmentality and technologies-of-the-self that occur at the level of the body, in which individual's self-regulation is conformed to obligations and conditions attached to free ART programmes participation.

The diet regimen is presented by the participants 'as an integrated part of everyday life' (Veen et al. 2010: 23), vital towards increasing their CD_4 count to fortify their immune system in fighting the virus (HIV) in their body. Therefore, dieting as a form of healthwork allows HIV-positive people to be active agents, whose interests mediate between individual's choices and structural constraints, with respect to how they respond to HIV diagnosis. Even though dieting is interpreted and understood by the participants differently from professional judgment, yet expert/professional knowledge about dieting becomes the resources that HIV-positive people deploy in HIV management. The account of Tossy (a 55-year-old-woman, living with HIV for six years) demonstrated this more profoundly:

> I used to go to seminars and workshops where I would be advised by health experts on the type of food to eat to boost my immunity especially fruits, vegetables etc, and I have been doing that; I am OK and healthy.

The professional terminology of dieting was acquired by the participants through seminars and workshops on HIV and are incorporated into the lay understanding of HIV management. The key speakers in most of the HIV seminars and workshops may include scientists, health educators, medical practitioners, and nurses, whose wealth of specialist knowledge/expertise and years of professional practice have imbued them with the latest health complications, new research direction, and recent developments in the field of HIV care and treatment.

However, most of the information on dieting is transmitted to the participants through the support group, this is seen after one of the members returned from conference, seminar, and workshops on HIV. The account of Segun (a 57 years-old-man, living with HIV for 13 years) revealed how professional knowledge on dieting is transmitted to people living with HIV through support groups:

> I have been to so many seminars where we talked about the current state of HIV, and its effects. Those seminars exposed us to many new developments, especially to participants and those who have never been opportune to be there. After the seminar, when I came back to the support group, I sensitised them about what I learnt. So, they gained from whatever I learnt. Since the members can reason very well, they gained from what I sensitize them on. Yes, I told them about what I learnt about dieting, but I never told them to stop taking their medications.

The transmission of professional knowledge on dieting is the reinforcement of governmentality in a taken-for-granted pattern by healthcare professionals without knowing it in advance. This is because the purpose of health professionals is to produce individuals who prioritise self-governance of health that affirm the sanctity of technologies-of-the-self. Since governmentality depicts self-governance at the micro-level to regulate the behaviours of the population, then transmitting the professional knowledge on dieting to lay groups like HIV support groups is the continuation and expressivity of governmentality agenda, whose goal is to conduct and regulate the behaviour and conducts of people living with HIV to produce healthy subjects in a certain way.

The professional information about dieting and the changes that accompanied its practices in the daily lifestyles of participants are not suggested by counsellors, but by scientists, health educators, medical practitioners, and nurses in conferences and seminars, and then transmitted to people living with HIV through the lay network of support groups. Accessing these webs of expert knowledge on dieting serve as vital resources for HIV-positive people in updating their lay understanding about the importance of dieting to support their treatment and for the overall maintenance of their health and well-being. Therefore, dieting constitutes part of healthwork because the participants considered it as a way of disciplining their individual bodies and enact ethical self-care regime through eating of certain foods as part of how they can manage their conditions alongside medication-taking, to increase their CD_4 count and rebuild their immune system, to suppress the virus, and prevent its multiplication in their bodies, and minimise deterioration in their health status.

4.2.7 Support group participation

The participation in support groups helped to produce a kind of subjects (individuals) that prioritise the disciplining of individual bodies and the enactment of an ethical self-care regime through shared advice and information. Support group is a subtler forum, where governmentality and technologies-of-the-self intersect in the participants' quest to maintain a healthy lifestyle. Support groups as patient-led organisations (Dibbs & Yardley 2006) have provided important social and support bases for people with chronic illness, and valuable to the adjustment to their conditions (Steffen 1997; Molinari et al. 1994; Dibbs & Yardley 2006). In the HIV context, support groups are a lay network, created by HIV-positive people, to share their lay knowledge on how to respond to their HIV diagnosis and manage their condition effectively. In the Nigerian context, HIV-support groups are formed by the HIV-positive people, at the health facility where they receive treatment.

Following Barlow et al. (2000: 54), HIV-support groups in Nigeria, are similar in nature to other self-help groups where 'only lay members and leaders can play an active role'. The account of Johnson (a 57 years-old man, living with HIV for 12 years), who is also one of the executive officers of a support group, gave an interesting account that demonstrates how executives of the support groups helped to contribute to the health and well-being of their members:

> During support group meetings, we encourage and enlighten our members how to live a positive life with HIV by using their medications daily and by eating good foods. Some people regard themselves as unworthy because of HIV and look down on themselves. It is through the support group that we advise and encourage them about how to live a fulfilled life regardless of having HIV. If any members have complaints, the person shares it and we discuss it together.

The executive of the support groups appropriated and arrogated to themselves counselling knowledge to educate other members especially the new ones about how to undertake healthwork and resolve complaints that stemmed from medication adherence, dieting, disclosure of HIV diagnosis to a spouse (as demonstrated in Segun's account on dieting above). The support group therefore helped to access health knowledge, empowering the members to be productive and live positively with HIV. The executive participants presented themselves as leaders, bosses, and experts that possessed a web of knowledge that is useful to members. While the members, especially the new ones (using the account of Bohun below), presented themselves as the recipients of expert information from older members and the executive officers, that are critical to managing their HIV condition. Despite this divergence, the participants considered support group participation as the 'new forms of collective care-taking' (Adamsen & Rasmussen 2001: 910), aimed at sharing the coping strategies of individual patients (Borkman 1997), with respect to dieting, medication-taking and living positively with HIV condition.

In deepening the understanding how support group participation fosters healthwork of people living with HIV in Nigeria, the account of Bohun (a 45-year-old-woman, living with HIV for three years) demonstrated how participation in the support group helped to support treatment in HIV context:

> When I first attended the support group meeting, I was weeping but they comforted me. Then, someone now used himself as an example, saying his child is not infected with HIV, and that he has been tested undetectable because he has been taking his medications daily and as instructed, yet he never stopped taking his drugs.

From the participant’s account, a support group is a convergence platform that provides a sense of belonging to HIV-positive people, to share similar problems and do something about it (Richardson & Goodman 1983). The participants do not have to worry about who knows about their HIV positive status because support groups provide a haven for members to talk about difficult issues, following shared and similar experiences of others in the support group. The participation in the support group thus helped members to reduce the burden of their illness. As a form of healthwork, the participation in a support group is considered by the participants as a resource and support network needed in battling stigmatisation and discrimination and helps in rebuilding the confidence and strength of newcomers through the stories of experienced people in the support group (Paudel & Baral 2015; Liamputtong et al. 2009). This encourages the new and existing members to work towards living healthier and longer lives.

From the participants’ account, the participation of HIV-positive people in the support group is critical to HIV management because of solidarity and encouragement from other members, helps to prevent anxiety, brooding and depression that could worsen the participants’ health. The support group therefore constitutes a social support mechanism that acts as a bridge between medical and emotional needs, where participants share experiences on how to live positively with their conditions. Participation in a support group as a form of healthwork to HIV-positive people because the participants considered support groups as a resource to manage their health effectively by offering them a sense of adjustment, coping skills, practical advice in going through treatment, and other HIV/non-HIV-related issues affecting members positively in everyday life. The health and other information acquired through the support groups enabled the participants to discipline their HIV bodies, by engaging in an ethical self-care regime that prioritises self-regulation of their behaviours.

The findings in this study share similarities with previous studies that affirmed the centrality of support group participation in empowering the patients to be productive; freed from bureaucratic and professional domination; reducing the burden of illness; accessing health knowledge; minimising the suffering they experience and be able to talk about difficult issues (Jurick 1987; Trojan 1989; Gray et al. 1997; Wituk et al.

2000). However, these studies only examined support groups within the context of group characteristics, recruitment into support groups, activities of the groups, the rise and growth of support groups, without exploring the participation in support groups as a form of healthwork, an area which this study has helped to address.

4.2.8 Internet Use

In addition to support groups where HIV-positive people access professional/expert knowledge from their lay members, the participants develop their lay knowledge of HIV management based on access to the Internet. The professional/expert knowledge as Hardey (1999; 2001) noted, is accessible to lay people with a computer linked to the Internet. In fact, most of the HIV-related information online is professional/technical knowledge that was written in a way that is fully accessible to lay people for easy understanding. The information obtainable from the internet would enable the participants to undertake responsible self-governance of their health.

Following the advent of e-health, M-health and social media, lay people can now utilise Facebook, Twitter, YouTube, blogs, emails, automated SMS and 'mobile wireless computer technologies such as smartphones and tablet computers' to access health and medical information (Lupton 2012). This is what Nettleton (2004) regarded as 'e-escaped medicine', which implied that the HIV body accessed through viral progression, has escaped from 'the boundaries of the clinic or the hospital' (Nettleton 2004: 669) and becomes more viewable through electronic information on the Internet. Although over 26 percent of Nigerians have access to the internet in 2016 (Freedom House 2017), yet the Internet thus serves as a resource that participants utilised to be acquainted with the current state of HIV research and knowledge.

However, not all participants have access to the Internet, as only seven participants indicated that they used the Internet to access information. The differences associated with Internet use are defined in terms of educational attainment and leadership position. Four of the participants who used the Internet have bachelor's degrees and the rest do not have a bachelor's degree, but only used the internet to access information due to their leadership position in the support group, which compelled them to seek more information. Generally, the participants who accessed the Internet, are looking for information that can help to support treatment and manage their health effectively. This was evident in the account of Joy (39 years-old-woman, living with HIV for 12 years) who sourced for more information on the internet about HIV:

> Yes, I look for additional information because I was always on the Internet to know the latest about HIV and AIDS. What is going on in the nation and outside the country.

Accessing HIV information from the Internet helped to create a new form of life where people living with HIV sought to reduce their dependence on clinicians and other healthcare professionals for treatment and to find out about the other latest developments concerning HIV. However, the educational background of the participant (as university graduate) might also shape her desire to seek additional information. Nevertheless, Internet use constitutes healthwork to the participants because it provides information on how to live a healthy lifestyle and manage their conditions effectively in everyday life.

On the other hand, participants who do not possess a bachelor’s degree, accessed the Internet for information due to their leadership position in the support group. Johnson (a 57-year-old-man, living with HIV for 12 years) is part of the executive of a support group and in the immediate past, a state chairperson of a network of people living with HIV and he did not attend higher education. Johnson’s access to information through the Internet stemmed from his leadership position:

> Apart from working with civil society organisations where I got a lot of information, I also used the Internet as a source of information on HIV where I got a lot of new information and where I will be informed of new developments on HIV/AIDS.

In comparison with Johnson’s evidence in the previous section on support groups, Johnson’s account on Internet use could give a cue that the quest to furnish support group membership with information might have influenced the need to access the Internet for more information, as his account above revealed. The participants made a routine use of the Internet within the health context of their everyday lives, which is contingent upon their HIV conditions and the leadership position held.

Generally, through the Internet, participants may be able to get an update on a report of HIV clinical trials, new developments in HIV drugs, and outlines of new research on HIV that could have far-reaching implications on how they manage their conditions. The HIV body is gradually being mediated by the information obtainable through the Internet as well as the ones obtained from the clinic or hospital setting. In this sense, information on HIV bodies is being refashioned in cyberspace, and conceptualised in terms of information flows that are accessible to people living with HIV. Therefore, the Internet has the potential to increase participants' sense of control over HIV (Broom 2005). The account of the participants revealed that surfing the Internet for useful health/HIV-related information was considered as healthwork by people living with HIV in Nigeria and constituted e-escaped medicine where participants do not rely entirely on healthcare professionals but reinforced their lay understanding of HIV outside medical settings (Watson 2000; Lawton 2003; Nettleton et al. 2005). The information obtained through the Internet enabled the participants to undertake disciplining of their individual bodies and the enactment of an ethical self-care regime, where scientific terms and jargon on HIV were understood in the practice of safe sex, prevention, treatment, and care (Rosengarten 2009). This would enable the participants to have fruitful consultations with health professionals without challenging expert/professional knowledge.

4.3 Discussion and Conclusion

This chapter presents a lay construction of healthwork by the people living with HIV in the Nigerian context. The findings in this chapter revealed two central findings: the first is that healthwork is the practices that HIV-positive people do to minimise deterioration in their health. HIV-positive people define HIV diagnosis as real in its consequences to their health, and therefore, respond by engaging in healthwork as a means of managing their conditions. The second is that healthwork is a taken-for-granted kind of governmentality and technologies-of-the-self that participants undertake in discipling of their bodies and maintaining health in everyday life. The practices of healthwork, therefore, stems from a lay interpretation of the HIV condition. The findings in this chapter revealed that there are other practices that HIV-positive individuals undertake around their health other than simply adherence to medications. These practices include the following components/elements: spirituality, testing, counselling, concealment, adherence, dieting, support group participation; and Internet use. Healthwork is the umbrella term for these practices that HIV-positive individuals undertake around their health.

The findings in this chapter revealed three other findings. The first is that some practices of healthwork especially testing, counselling, adherence and dieting are reflections of governmentality and technologies-of-the-self. With governmentality and technologies-of-the-self, the enactment of healthwork through the body has enabled the participants to engage in responsible self-governance that prioritises the disciplining of their bodies through an ethical self-care regime. Governmentality is exercised through healthcare professionals, who use their expert knowledge to ensure subtle compliance through the subjectivity of the participants, who are conforming to the rules and conditions for continuous participation in free ART programmes. With technologies-of-the-self, antiretroviral drugs constitute the medical technology that participants used to observe and monitor their own actions and behaviours through adherence and dieting that emphasised the operation of disciplinary power.

The second insight is that being diagnosed with HIV, does not automatically make HIV-positive people to be lay experts on HIV, as Prior (2003) has confirmed. Having been diagnosed with HIV is not enough to make HIV patients become lay experts, without the incorporation of expert knowledge (Williams & Popay 1994) into their lay understanding through healthwork. In this regard, healthwork affords HIV-positive people the opportunity to appropriate and incorporate expert knowledge of CD_4 count, viral load, adherence, and dieting into their lay understanding of HIV vis-à-vis medical encounters (such as counselling and testing).

The third insight is that the most important part of healthwork is adherence. This is because without adherence, a lived experience of HIV is impossible. However, adherence is not the only part and form of healthwork. There are other practices undertaken alongside adherence to support participants’ treatment. Adherence involves daily practices that are not influenced by socio-demographic characteristics, while other forms of healthwork are practices that are less frequent, subject to educational background, leadership position, and the individual’s choice. Concealment, dieting, and spirituality are subject to the individual’s choice and preference, while Internet use hinges on education level and leadership position of the participants.

It should be acknowledged that spirituality, concealment, and support group participation are still shaped by larger social processes and institutions such as culture, religion, and government intervention. Similarly, while healthwork is an individualised process, it is influenced by macro forces (such as government policies and structures that govern treatment access). This indicates the importance of the context/structure in the practices of healthwork, thereby recognising the impact of structure on individual actions/choices. Nevertheless, the participation in any of these elements, thus constitute healthwork that HIV-positive individuals undertake individually.

This finding broadly aligns with the studies of Mykhalovskiy and his colleagues (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008) that healthwork is utilised to support treatment. This is because HIV-positive individuals engage in testing because they want to know the treatment is actually working, they pray in the hope that the treatment will work, they go on the Internet to find out more about treatments and how they can be effective, they diet to ensure that treatment is not disrupted. Healthwork was undertaken around the participants' health to support treatment in Nigeria in the same way that it was in Canada. The contexts differ but the practices are largely aligned between both countries.

What is fundamentally different between my research and that of Mykhalovskiy and his colleagues, was the differences in the way in which healthwork was undertaken. The conceptualisation of healthwork, as studies of Mykhalovskiy and his colleagues showed, are purely a Western derivative that obscures the social reality of HIV or the socio-cultural understanding of health and illness in developing countries, especially in the Nigerian context. For instance, spirituality as shown in this study, as a form of healthwork, has been observed as part of HIV-positive people's response to HIV diagnosis (Parsons et al. 2006; Kremer et al. 2009; Trevino et al. 2010; Caixeta et al. 2012; Steglitz et al. 2012; Molzahn et al. 2012), but there is lack of engagement in the works of Mykhalovskiy and others. This study is therefore an extension of healthwork, framed within a specific cultural context and practice. This contribution further highlighted how health work is shaped by and manifested in Nigerian cultural milieu.

Furthermore, the findings in this study do not suggest that these elements of healthwork could fully explain the response of HIV-positive people or other sufferers of chronic illnesses in other contexts. For instance, spirituality as a form of healthwork in the Nigerian context, may not be embraced in other contexts, but chronically ill and HIV-positive people in different contexts may participate compulsory in testing, counselling, and adherence as the basis of their healthwork.

Other areas where similarity exists in both studies was in the context of the role of the support group, where HIV-positive people meet and share their experiences of HIV management in relation to the experiences of others in the group. For instance, Mykhalovskiy (2008) observed that community-based AIDS organisations, which is support groups in my research, produce health information and 'translate medical and scientific knowledge into easy-to-read formats' for HIV-positive people (Mykhalovskiy 2008: 153), though, participation in the support group was never regarded as part of the healthwork in studies of Mykhalovskiy and others. The consensus in both studies revealed that support groups constitute a lay network where HIV-positive people obtain shared information about medications, how to manage their condition effectively through the experience of others, and as a platform for discussing HIV and non-HIV related issues that are relevant to their everyday lives.

These findings in both studies therefore found empirical support that support group

articipation enhances and empowers the patients' increased health knowledge and coping strategies for people in different conditions, following similar experience of others in the support group (Lieberman & Videka-Sherman 1986; Trojan 1989; Williams 1989; Karp 1992; Gray et al. 1996; 1997; Damen 2000; Borkman & Giddings 2008; Narasimha et al. 2017). Despite this similarity, another area of divergence can be seen in the context of the acquisition of relevant health information. The findings in this chapter have revealed that there are other avenues like the Internet and seminars/conferences where people living with HIV acquired health and treatment information other than through a support group that was evident in the studies of Mykhalovskiy and McCoy (2008), Mykhalovskiy et al. (2004) and Mykhalovskiy (2008).

Conclusively, this chapter has observed that healthwork is more encompassing than adherence, as the most important practice that people living with HIV undertake around their health, to support their treatment in daily life. Even though adherence is part of healthwork and constitutes the most important component of it. Healthwork are thus, practices that involve disciplining of individual bodies and the enactment of an ethical self-care regime, with a view to producing responsible individuals capable of undertaking self-governance of their health in everyday life. In this regard, healthwork is central to HIV management in everyday life.

Despite unravelling these components of healthwork in HIV management, the fundamental question about the consequences of this healthwork on the biography of HIV-positive people are yet to be explored. Since healthwork depends on the diagnosis of a condition, diagnosis has serious effects on biography or facilitates discontinuity in the chronically ill-persons' biographies. Therefore, the consequences of healthwork on everyday lives of HIV-positive individuals are the impact of healthwork on these biographical issues (of biographical temporality, the body, and self/identity) that will be explored in subsequent chapters five, six, and seven respectively.

CHAPTER FIVE

BIOGRAPHICAL TIME AND HEALTHWORK IN HIV MANAGEMENT

5.1 Introduction

The previous chapter explored the lay understanding of healthwork of HIV-positive individuals in the Nigerian context. This chapter is devoted to further exploring healthwork with respect to its impact on the biographical temporality of HIV-positive individuals. HIV is a chronic illness that does not yet have a cure, but it can be managed over time. HIV management is a biographical experience structured by its temporal essence. Time is woven into the biographical structure of HIV management, meaning that an HIV diagnosis accelerates a person's biographical awareness of temporality, which they may have previously taken for granted. The concept of biographical time was first conceived by Corbin and Strauss (1987) in their study on biographical work. They argued that chronic illness affects a person's temporal sense, disrupting 'the rhythm of the social world or the anticipation a person has of living out their days into old age along the lines of the established temporal rhythms of childhood, adolescence, adulthood, and old age' (Jowsey 2016: 1095).

Within the context of HIV, the concept of biographical time is used to manage the impact and the consequences of the condition in the everyday lives of HIV-positive people so that those living with HIV can make sense of their past and present events, as well as their future expectations, in the light of the disrupted circumstances caused by their diagnosis and the social conditions in which they live with HIV. As stated in Chapter Two, a key limitation with these earlier studies of biographical time and HIV is that the participants used in those studies had been diagnosed prior to 1996 before HAART was introduced. If the participants had been diagnosed during the HAART era, would the consequences of HIV on biographical temporality correlate with the experiences of those who had been diagnosed prior to HAART? The study into the biographical temporality of HIV-positive individuals in the HAART era remains a largely uncharted terrain. The dearth of research on this topic raises two important issues. The first issue is how HIV disrupts the biographical temporality of people living with HIV in the Nigerian context which has not been addressed in the literature. The second issue revolves around the question of how healthwork helps to rebuild/reconstruct the broken and disrupted biographical temporality of HIV-positive individuals. Participation in healthwork has temporal consequences in the daily routine of HIV-positive individuals, and such temporal sequences are woven into the biographical temporality of HIV-positive individuals. In this sense, healthwork is central to the reconstruction of disrupted biographical temporality of people living with HIV.

This chapter addresses these gaps. Section 5.2 explores how HIV disrupts the biographical temporality of HIV-positive individuals in the Nigerian context. Section 5.3 explores the role that healthwork plays in the reconstruction of broken and disrupted biographical temporality of people living with HIV.

5.2 HIV disruption of biographical temporality in Nigeria

Bury's (1982) concept of biographical disruption helps to understand how chronic illness disrupts the daily activities of its sufferers and alters the course of their biographies. The findings on biographical time in this chapter found empirical support for Bury's articulation. It was observed that the intrusion of illness into participants' lives often results in the disruption of biographical time, where the afflicted person is forced to compare the body of the present and future with that of the past, thereby 'resulting in a profound sense of loss and changed identities' (Corbin 2003: 259). The forms of biographical temporality—past, present and future—are unable to exist on their own, as they are woven together or constitutive of each other, like an unending wave in an individual's personal biography.

The HIV-positive participants in this study reported consequences of the disruption to their biographical temporalities that fall into two categories: discontinuity and uncertainty. These categories will now be discussed in turn.

5.2.1 Discontinuity

The temporal order and sequences in which the participants' plans were anticipated, lived, and achieved were thwarted and discontinued following the onset of HIV. The social circumstances in which the participants had lived their past lives enabled the onset of HIV to foster a sense of nostalgia and made them feel they were living in the past, given the discontinuity brought to their career, education, business/finance, and marital relationship. The moment the present was thwarted, the new present[9] emerged. This discontinuity was facilitated by cultural influence and social factors that shaped the individual's experience of temporality. The new present was the temporality that ensued following discontinuity, in which the participants continued to live their present lives under different circumstances.

With discontinuity, the plans that participants had anticipated in the past and lived in the present were discontinued, terminated, and prevented from being carried forward into the future after they were diagnosed, not only by the onset of HIV but also the social circumstances/conditions in which the participants lived with HIV. The consequence of this discontinuity was the experience of being nostalgic about the social relationship that formed the experience of past living.

Living in the past means longing to bring back not only the past life or what was achieved in the past, but also the social milieu that accompanied how most of one's ambitions were achieved in the past, or how the past life was lived. In this sense, the past is considered as better than the new present. Living in the past was reflected in the participants' refusal to consider their new present as significant due to the inability to recover opportunities that were lost in the past and the social life that accompanies it. The new present was lived in dissatisfaction and sadness, because of its inability to replicate the reality of the past and present that were destroyed and thwarted by HIV.

HIV brought discontinuity to the life of Praise in the context of her business/finance life. Praise is a 52-year-old woman who has been living with HIV since 1991. She had a primary school education. Prior to the onset of HIV, the social status of Praise was that of a small business entrepreneur, who had a hotel business, properties (land and houses) and a strong financial wherewithal. Praise is a single mother with two children, whose past was marked by a prosperous business career with sizeable

---

[9] When HIV ensued, it disrupted the biographical temporality of the participants at the present. After disruption, the biography of HIV-positive individuals does not remain the same as it was before the disruption. The temporality that ensues after the disruption is the new present, that may be different or like the previous present in the context of biographical plans. The life after HIV does not automatically transmit into the future of the participants; rather, it constitutes the new present. The new present is the new circumstances that participants found themselves in or oriented to, that may be similar to or different from the present states they were experiencing before the serious disruption to their everyday lives.

financial returns. The narratives of Praise reveal how the onset of HIV led to financial problems that thwarted her social status around a burgeoning business enterprise:

> I had wanted to go into business when I was small because my mom was a petty trader, who taught me basic knowledge of petty trading… Prior to HIV, I live a good life. I have money and I don't experience any hardship. I eat whatever I want to eat. I can even eat six times in a day because I have the business that was making money. In fact, I have money and I worked hard for it. When I was diagnosed with HIV, I was told there is medication for it. The cost of HIV medication at the time was ₦20,000 (£666) then per month. First, I spent all the money in my bank account. Later I sold my land, my house and car to buy the drugs. Though, there was no way I can afford the medication cost without selling my properties. All my money, properties and business went with HIV. After spending all my money on medications, it came to a point that I came out and went to [my] state government to assist in subsidising my medical bills… Now I am just doing this job (HIV counsellor) because I have no choice and I have nothing to do. This job is a low-pay job, and the salary is not enough to feed my family. If not for HIV, I would not be doing this. Just imagine, before the middle of the month, I have already run out of money, and I will start to borrow money to feed myself. Every day, I used to think that if not for this virus, I would not be here, and I would have been financially stable with expanded business. Some people that I know who started business the same time as mine, are richer than I today.

The onset of HIV destroyed and thwarted the business and financial base of Praise's life and facilitated her current spate of nostalgia, fostered by an inability to replicate the social condition of the past that was underpinned by financial wherewithal. The time of diagnosis was the social factor that shaped the experience of discontinuity in Praise's life following biographical destruction of her business and finance. At the time Praise was diagnosed with HIV, there was limited knowledge of HIV, coupled with discrimination and stigmatisation against people living with HIV, which was rife because of the negative cultural understanding of the illness in Nigeria. Furthermore, Praise was diagnosed in 1991, in the pre-HAART era when the cost of antiretroviral drugs was expensive and there were no free medications for HIV-positive individuals. In 1991, there were two known drugs to treat HIV across the world, namely Stavudine (d4T), which was approved by the United Stated Food and Drugs Administration (FDA) in 1991, and Zidovudine (AZT) that was approved in 1987.

Both drugs were expensive in Nigeria, and even today the Nigerian healthcare system does not have the structure of health insurance to cover the cost of HIV treatment. HIV triggered the bleak reality of the huge medical bills needed for Praise to manage her condition. HIV destroyed her financial base and her business plan because the funds needed to sustain her business had to be redirected to pay her medical bills. The biographical disruption quickly turned into biographical destruction for Praise, when she terminated the business and sold off her properties with a view to offsetting the medical bills arising from her HIV management.

The discontinuity experienced by Praise was shaped by the timing of diagnosis, when HIV treatment was expensive and there was lack of free ART programme at the time, which led to her inability to get back to the financial past she'd left behind when she was diagnosed. When compared to the past, the downward social immobility experienced by Praise in the present, triggered a sense of nostalgia—where the participant refused to consider the new present as important because of the inability to replicate the social status associated with financial wherewithal that characterised her past business adventures.

The consequence of the HIV disruption was the destruction and loss of financial means and discontinuity of Praise's business career, which she was never able to recover, and returned to the social status of financial wherewithal. Becoming an HIV counsellor represents the new social circumstances that the new present fostered for Praise, following the discontinuity of her business career. Her unhappiness with the new present was caused by financial constraints, whereby the income from the current job was insufficient to cover the cost of living when compared with the past. Praise is living in the past because of her frustration with the current social condition of dire financial situation, and the resultant desire to go back in time to a period when her financial position was so much better.

Praise's experience of discontinuity in the pre-HAART era is reflected in contemporary experiences of diagnoses, especially for those people who have been diagnosed in the present. However, the social circumstances of free ART programmes for testing and treatment have limited the financial impact of HIV diagnosis in the HAART era when compared with the pre-HAART era, where free ART programmes still impact on people's personal relationships due to persisting cultural factors.

In contrast to Praise, who was diagnosed in the pre-HAART era, HIV brought discontinuity to the career of Segun, a 53-year-old ex-army officer, in the HAART era. This indicates that the timing of diagnosis was not an important social factor as in the case of Praise. At the time when Segun was diagnosed, HAART was free in Nigeria, and the financial burden regarding the cost of treatment on the affected individuals was less. When he was in primary school, Segun had a life-long desire to become an army officer and it was something he strived for. He joined the Nigerian military at the age of 19. Segun has been living with HIV since 2004 and the diagnosis led to the termination of his military career, which he misses greatly:

> I was HIV positive when I was 30 something years. My past life was not bad, I was not living rough, like I told you I went into the army at a very tender age because that was what I dreamt of doing. As at 19 years, I was in the army after finishing my secondary school career, I was not a rough man. In the army, I coordinated myself very well and I never had any rough or bad way of living. Because of this issue of HIV, I was compelled to retire prematurely from the army. HIV scuttled everything that I planned and throw the future that I built for myself into disarray. Being an HIV counsellor is not what I really wanted to do. I am not happy with the job at the moment. Each time I reflect on my military career, I felt I lost a rare opportunity. There are many perks, allowances, foreign missions, and enjoyment that comes with it. Now, everything is gone and nothing again. I wish I could still be in the military.

HIV brought discontinuity to the military career of Segun and made any future progression of that career unachievable. HIV was the major disruptive factor that triggered discontinuity, but HIV onset alone might not have triggered discontinuity without the stigma around HIV, which emanated from the cultural understanding of HIV in Nigeria. As an institution, the Nigerian military is a microcosm of the Nigerian society and is not immune from the cultural inscription of HIV. Therefore, the discontinuity experienced by the participant in his career would not have occurred if there was no stigma around HIV in the country. Therefore, the social factor that shaped the experience of discontinuity was the cultural stigma around HIV, which found its expression within the institution of the military.

The disruptive consequence of discontinuity fostered a sense of nostalgia about the past, and the social relationship that underpinned it. Segun lived in the past and could not yet reconcile himself with the reality of the new present because of the past opportunities associated with the social status associated with a military career that are now considered lost and deemed irreversible. HIV, therefore, ushered in the biographical destruction of Segun's career and prevented it from continuing. It paved the way for a new present that was devoid of meaning.

To dissociate himself from the cultural conception that blames victims for being infected with HIV, Segun deployed the cultural metaphor of a 'rough life' when reflecting on his past life. He aims to dissociate HIV infection from the consequences of rough way of life. 'Living a rough life' in Nigeria means that a person is living a careless and promiscuous lifestyle (of risky and unprotected sex) without thinking about the consequences for their health. This narrative demonstrates the way in which the social interpretation of HIV hinges on the way the culture defines this devastating illness, leading to the consequence of moral shame for those who are unfortunate enough to be infected by it. According to the cultural inscription of HIV in Nigeria, HIV infection is self-inflicted and synonymous with those who are promiscuous, those who live a rough life of careless and unprotected sex (Smith & Mbakwem 2010; Tocco 2010). By separating his past behavioural conduct from promiscuity and unprotected sexual intercourse, Segun gave a positive impression of his self that detached his HIV condition from the suggestion of promiscuity that underpinned the cultural narratives of rough life.

The turning point in Segun's life arose when he was diagnosed with HIV, leading to the disruption of his previously unbroken biographical progression from his childhood through to young adulthood, and through graduation from high school into military conscription. Prior to the interview, Segun told the interviewer that he was forced to resign from the military when he failed a medical test in February 2004, a test conducted on all military officers commissioned for UN peacekeeping operations in Sudan. The cultural stigma around HIV as an illness that has no cure means that the participant could not be trusted due to the fear of contagion or spread of HIV within the military rank and file. The upset and rupture in Segun's biographical temporality began with the HIV diagnosis, and this rupture led to the discontinuity of his military career. Even though the participant was one of the beneficiaries of the free ART programme, the decision to resign might not have been informed by scientific evidence, but a cultural understanding of HIV that has pervaded every facet of Nigerian society.

The implication of discontinuity of Segun’s career was the loss of social privileges that accompanied a military career. The participant became nostalgic not only about the past, but the irredeemable nature of social circumstances that defined it, while the new present was not accorded greater importance in his temporal considerations because the social milieu that shaped it was different from that of the past. Discontinuity in Segun’s narrative was reflected on the way his future endeavour deviated from the aspiration of the past and the accomplishment of the present. Although Segun accepted the new present, his refusal to incorporate his current job and social circumstances into his new present was the outcome of nostalgia, fostered by discontinuity that was shaped by the cultural and moral panic around HIV.

While HIV disruption constituted discontinuity of Segun’s career, a different social circumstance was observed in the narratives of Lara (a 46-year-old woman who has been living with HIV for 12 years), who was diagnosed in the HAART era. Like Segun, the cultural stigma around HIV was the social factor that accelerated the discontinuity that HIV brought to the biographical temporality of Lara. The consequence of HIV disruption for Lara led to the discontinuity and cessation of her financial security and travelling/relocation plans:

> Before I was infected with HIV, I always thought of travelling to the United States. In fact, because of the economic situation in Nigeria, I wanted to relocate abroad to live there, work and settle there. My husband is an outgoing person that travels around the world a lot. He used to encourage me to travel out of Nigeria, and I have made it my number one plan. Then my husband wanted to be responsible for the cost associated with obtaining my travelling documents and processing my visa. But when I was diagnosed of HIV, I told my husband about it and he left the house and relocated to Canada with another woman. Now we are separated and that plan of travelling abroad has crumbled. With four children, I am more interested in getting money to take care of my children in terms of feeding, paying tuition fee and their welfare. Since this new US president came on board, getting visa to America is now tough and expensive, as many of my friends have been refused several times. HIV disrupted my travelling plan because it came at the time when it was easier for me and my children to get the visa, and when my marriage was intact, and husband was financially capable of enabling this. Now I have lost everything. I am not happy now because at the crucial period I lost the opportunity to change my own story and that of my children in a foreign land.

The stigma around HIV and the fear of contagion led to the disruption of the participant’s biographical plans. This cultural factor was further deepened by the dire economic situation that triggered the discontinuity of travelling and relocation plans of the participant. HIV did not only alter and change Lara’s expectations for travelling and relocation in the future, but it also impacted her family and financial situation. The disruptive consequence of HIV to the participants would have been minimised and be under control if the cultural stigma around HIV had not led to the discontinuity of the marital relationship, which was one of the social factors that led to the discontinuity experienced by the participant.

Another social factor that influenced the experience of discontinuity in the participant’s life was the financial constraint that prevented the actualisation of travelling abroad and her relocation plans. If the participant was financially viable and independent, the cultural stigma that led to her broken marital relationship would not have led to the discontinuity in the travel plans of the participant. The consequence of discontinuity was the inability to revert to the past and reclaim her lost travelling opportunity. Discontinuity bred nostalgia about the disrupted familiar relationship, which triggered the admiration for her past aspiration of travelling abroad that was deemed unrealistic in the new present.

Whereas HIV disruption constituted discontinuity for Lara in the context of her travelling/financial situations, a different fate was observed in the narratives of Ibukun (a 48-year-old woman, who has been living with HIV since 2004). Like Lara and Segun, the cultural stigma around HIV was the social factor that shaped the experience of discontinuity that HIV onset brought to the marital relationship of Ibukun. The consequence of discontinuity for Ibukun can been seen in the cessation of her marital relationship:

> When I was young, my important ambition then was to have a happy home, happy children, happy husband. It was when I was pregnant that I knew that I had HIV. You know then that people run away from HIV-positive people and discriminate against them. My husband packed his belongings from home and ran away from me when I told him that I got HIV. God takes all glory over my boy who is 14 years and now in high school. Of course, if my husband comes back, I will gladly take him back, but I don’t think that will happen because he had married another woman and had three children. HIV disrupted my marriage, and its scars will forever remain with me till I die. I decided not to remarry because I do not want to be a partaker of a generational curse in my

> family. The mother of my father married a second husband after the death of her first husband. My father was my mother's second husband. My two elder sisters are now with their second husband, respectively. I miss my husband and till today I am still at pain that he deserted me. Sometimes, I cried profusely not because of the good and bad moments we shared together, but because of the pain HIV brought to my life, especially my marriage… I feel boring and lonely now, and I wish I had not been infected with HIV, and I had wished my husband and I are still living together.

The participant's strained marital relationship was triggered by the cultural understanding of HIV in Nigeria, which led to the separation with her husband. The disruptive consequence of HIV for Ibukun is the biographical destruction of her marital relationship. The loss of the marital relationship was due to stigmatisation and the cultural understanding of HIV, which caused discontinuity to ensue. The resultant effect of discontinuity connotes living a boring and lonely life. The social effect of discontinuity was the loss of the participant's marital relationship, that triggered living a boring and lonely life. Living in the past means living in the empty present for this participant because of her refusal to let go of the past relationship and reconcile herself with the current reality of her marital relationship in the new present. In fact, the narrative of the participant that reads 'I miss my husband and till today I am still at pain that he deserted me' can be interpreted as the experience of living in the empty present, occasioned by attendant loss of the marital/social relationship that serves as a bulwark against loneliness. This finding found empirical support in the works of Davies (1997) and Pierret (2001). This experience of an empty present is part of a broader discontinuity that Ibukun experienced because of HIV disruption to her biographical temporality. The consequences of HIV disruption for Ibukun's marriage can also be seen in the resultant single parenting home where the familial responsibility of raising a boy lies with her alone, with all the attendant gender implications. The participant's orientation to re-establish continuity was further punctured by the myth that "generational curse" was the cultural belief, which undermined the agentic disposition for a new marital relationship.

The strain of separation and single parenting may have unimaginable effects on the children affected. For Ibukun, being diagnosed with HIV changed the social nature of nuclear familial relations into single motherhood or a single parent family, where parental responsibility (taking care of a boy) previously held by two people (husband and wife) later becomes that of Ibukun on her own. The gender implications of the disruptive experience of HIV to the biography of Ibukun can be seen in the loss of co-parenting, where responsibilities previously undertaken jointly by a father and mother are now being undertaken by the participant alone. This ensued due to the cultural stigma around HIV and the fear of contagion that triggered discontinuity in the marital relationship. The implication of this disruptive event is that women were more likely to experience severe emotional and personal issues following the breakdown of a marital relationship than men.

As a general theme for all these participants, the disruption caused by a HIV diagnosis thwarted not only the smooth and orderly temporal sequence implicit in their biographies, but also fostered biographical destruction of their past lives and ushered in a new present that was devoid of meaningful living. This discontinuity is shaped by the cultural stigma around HIV, which was underpinned by the cultural understanding of HIV and socially situated around stigmatisation. Other social factors that shaped the participants' experience of discontinuity in their biographical temporalities are time of diagnosis and financial constraints, the consequences of which were reflected in the participants' careers, marital relationships, and financial plans. The consequence of discontinuity caused by HIV disruption was individually experienced, but was triggered by these cultural and social factors in which the participants' temporalities were forged and experienced. The experience of being nostalgic about the past stemmed from the present predicament, where participants were frustrated about their inability to return to the past lives they left behind when they were diagnosed. Therefore, living in the past means the refusal to accept or fully live in the reality of the new present.

5.2.2 Uncertainty

Uncertainty is the expression of worry and a lack of confidence about the future, and this uncertainty is the reflection of the social circumstances caused by the lack of credible alternatives to the future course of actions and events. Two social factors shaped the experience of uncertainty: lack of HIV cure, and the sustainability question regarding the continuation of the free ART programme in Nigeria. The participants' concerns about the sustainability of the free ART regime exists due to a lack of HIV cure. Therefore, the lack of a cure is a central factor that triggered uncertainty around the sustainability question of a free ART programme in the future.

These social factors fostered uncertainty in the participants' sense of an imagined future, previously assumed to be assured and secured.

Living in the uncertain future is an individualised experience that reflected on how HIV diagnosis disrupted the temporality of the participants and prevented them from living positively in their new present, thus stopping them from pursuing their aspirations and engaging meaningfully with the opportunities available to them. The participants were living in the uncertain future, constantly worrying about whether the current regime of free antiretroviral drugs might be stopped in the future, leading to devastating consequences for their health.

The narrative of Sida (a 36-year-old woman, living with HIV for nine years) provides an interesting insight into how HIV-positive individuals in the new present are living in the uncertain future, constantly worried about what the future holds for them in relation to their HIV condition:

> If there is anything I'm unsure about is the future. The concern that I have every day on my future is about this drug that I am taking. My only prayer is that God will enable the government that is providing these free drugs to people living with HIV not to stop providing it, otherwise my future will be jeopardised. If cure is not found, and the government continues to provide for these drugs freely, my future will be assured, and I will be able to take my children to the level they will be able to fend for themselves.

The free ART programme was initiated in 2002 by the Nigerian government to provide free HIV treatment to people living with HIV (Monjok et al. 2010). Therefore, uncertainty is socially situated around a lack of cure and discontinuation of the free antiretroviral therapy programme, as the participant is unsure and worried about the future because her imagined future is tied to the future of the ART programme in Nigeria, whereby free HIV medications are available to people living with HIV.

The participant's narrative further emphasised the connection between the future of antiretroviral drugs and childcare, where her duty of care to her children could be disrupted by a sudden halt of free antiretroviral drugs. The familial relations associated with childcare comprise the structural context of experience and social basis of existence that continues to define the primacy and centrality of free antiretroviral drugs in the life of the participant. The discontinuation of the current regime of free antiretroviral drugs connotes a truncation of the participant's notion of the future, that relates more broadly to her vision of the futuristic state where the future of the participant is the future of her children. The implication of this is reflected in a social relationship in which the care and upbringing of the participant's children depends on her health, and which in turn is dependent on whether free antiretroviral therapy will continue in the future or not.

Another participant, Moji (a 38-year-old-woman, living with HIV for nine years), gave a narrative that underscores how HIV disrupted her temporal sequence and ushered in an uncertain future, based on her concerns about the future availability of free antiretroviral therapy in Nigeria:

> The only hope I have in managing this condition in the future hinges on this drug. If I used it the way I am supposed to use it and the drugs are still freely distributed by the government and there is no scarcity of these drugs in the future, I know that I will live long in order to achieve my future plan of further education and remarriage. I am a bit worried that, no matter how good my future aspirations and plans are, those plans cannot be realised if these drugs are not available in the future.

The expression of uncertainty was reflecting social conditions associated with the lack of alternatives and choices around HIV curative therapy, and potential discontinuation of the free ART programme in the future. The imagined futures of HIV-positive individuals are significantly tied to the continued availability of free antiretroviral drugs. Moji was worried that, regardless of how bright her future ambitions, aspirations and plans might be, they were still tied to the continued availability of the ART programme. The onset of HIV diagnosis, occurring when Moji was a high school graduate, disrupted not only her quest to attain higher education qualifications, but also disrupted her marital relationship. However, the normalisation ushered in by the free antiretroviral drugs programme has enabled her to reconsider her future plans for remarriage and further education.

The discontinuation of free drugs in the future would have devastating health consequences for HIV-positive individuals who may experience affordability problems. The problem of affordability in the Nigerian context is resolved by therapeutic citizenship (Nguyen et al. 2007) that enabled antiretroviral therapy to be free at the point of delivery. Therefore, the imagined problem of unaffordability is the social condition that triggered the wave of uncertainties that could be disruptive to the participants’ imagined future. Living in the uncertain future at the new present connotes that the participant was worried about the way that affordability might cause problems for her future aspirations and undertakings.

Generally, the findings in this section have unpacked how the onset of HIV has created disruptive consequences for the biographical temporalities of the participants, and these consequences are expressed in the disruption and destruction of various parts of their lives: career, travelling plans, marital relationships, and financial plans. This disruption caused by HIV onset fostered a discontinuity that was instrumental to the sense of nostalgia that participants experienced when they refused to fully live with the reality of the new present and let go of their past lives. This sense of discontinuity was shaped by social factors such as cultural stigma around HIV and financial constraints that the participants experienced in their lives. Therefore, living in the past depicts that the new present of the participants was being lived in dissatisfaction and sadness, due to their inability to reconcile the past with the present that had been destroyed and thwarted by HIV.

Furthermore, it was also observed that HIV disruption brought uncertainty to the participants’ futuristic sense that was assumed to be assured and secured, and this uncertainty was shaped by the circumstances created by the lack of a cure for HIV and a sustainability problem posed by the continued funding of a free ART programme in Nigeria. Living in the uncertain future was characterised by existing social circumstances that HIV activated in the imagined future of the participants. Therefore, the participants’ new present was characterised by living in the uncertain future, as their sense of imagined future was connected to the future of the ART programme. This observation demonstrates that biographical temporalities that HIV-positive people experienced in their lives are shaped and reshaped by cultural and social factors that influence such temporal experience. In this study, this disruptive consequence of HIV fostered the experience of discontinuity and uncertainty that was shaped by the aforementioned social factors. The consequences of these disruptions facilitated the emergence of the new present that has profound implications for an imagined future.

Reconstructing this disrupted sense of biographical temporality requires a mechanism that can help in reshaping the premises upon which the previously disrupted plans were developed. This mechanism requires actions and activities that are within and outside the normal daily routine of the participants, which healthwork symbolises. The role of healthwork in achieving this reconstruction is addressed in the next section.

5.3 Biographical time and healthwork in HIV management

The fundamental question of how to rebuild and reconstruct a broken or disrupted biography has been central to Corbin and Strauss' (1988) research on biographical work. The notion of 'accommodation' (Corbin & Strauss 1988: 255) consists of psychological approaches to aligning and adapting illness into everyday life. However, rebuilding broken or disrupted biographies cannot be achieved solely by accommodation, because studies have shown that patients tend to resist and fight the illness rather than accepting, accommodating or integrating it into their everyday lives (Brooks & Matson 1987; Robinson 1988; Boeije et al. 2002).

Apart from accommodation, the notion of coping has been articulated (Bury 1991; 2001; Locock & Ziebland 2015). Coping has been defined as 'the cognitive processes whereby the individual learns how to tolerate or put up with the effects of illness' (Bury 1991: 460). Coping, in this sense, connotes how people maintain and sustain a sense of worth in the face of a debilitating chronic condition (Bury 1991; 2001; Locock & Ziebland 2015). However, what is problematic with accommodation and coping is that both are just internal mechanisms for managing the effect of chronic illness. Internal mechanism here means something that is individualistic and oriented to an individual's cognitive or psychological state. Therefore, accommodation and coping are subjective and restricted to the individuals involved. Reconstructing the disrupted biography as well as biographical temporality requires more than accommodation and coping, and cannot be undertaken without the imprimatur of social actions and practices that are not just within and outside the internal/subjective state and normal daily routine of the patients (Hyden 1997).

Healthwork comprises of actions, activities and practices that are within and outside the normal routine of people living with HIV. In the context of biographical time, reconstructing disrupted biographical time requires elements of healthwork such as concealment, counselling, testing, and adherence. In this study, healthwork was found to have helped in reconstructing the biographical time of the participants.

These forms of healthwork are undertaken under the temporal context of the new present. From the narratives of the participants, two categories emerged where healthwork plays a role in the reconstruction of the disrupted biographical temporality of HIV-positive individuals. These categories are as follows: continuity and positivity. They will be explored in the following sub-sections.

5.3.1 Continuity

Healthwork offered continuity to the participants following the disruptive consequences of HIV for their career, business, marriage, travelling plans, and financial plans. The social factor that influences participants' experiences of continuity was the changes in government policy on HIV/AIDS in Nigeria. In other words, the continuity that ensued in the temporal life of the participants is socially situated around government policies of free ART programmes, which was the social condition that made the participants reconstruct some semblance of continuity to their aborted biographical plans in the aftermath of HIV diagnosis.

The healthwork of the participants leveraged on this social condition, and fostered continuity that enabled the participants to go back in time and pick up from where they left off when they were diagnosed and make the most out of their new present and eschew living in the past. With continuity, the participants accepted that social relationships that underpinned past lives were lost, but the old biographical plans associated with past could still be achieved, and hence saw the need to re-establish continuity. In continuity, the fundamental question of when participants intend to achieve the continuity in their biographical temporalities was missing. The plausible explanation for this revolves around the social circumstances/conditions in which the participants live following HIV diagnosis. For instance, the participants whose marriages, finances, and travelling plans were disrupted by HIV onset cannot say precisely when they hope to achieve continuity, but they are hopeful and confident that such continuity would occur at some time in their lives. The social circumstances of poverty and a financial bottleneck might have constrained or delayed the continuity that some participants who experience disruption in their finances or travelling plans had hoped to achieve immediately after being diagnosed with HIV. It is these social circumstances/conditions that will determine the temporal question of when in their pursuit of continuity.

Despite the discontinuity brought to the educational plans of Moji (a 38-years-old woman living with HIV for nine years), healthwork enabled her to return to higher education and continue with the aborted present engagement under new social circumstances and in a different temporality:

> Counselling helps me to know more how to live positively with HIV, and HIV counsellors made me to realise that I am not different from other people who are not infected with HIV and that continued sadness about my condition will not solve the problem. Now I can do whatever I want to do as long as future permits. As long as I am using my medication, there is nothing I can’t do. Now I am starting a diploma programme at a Polytechnic in three months’ time, but when I thought of some of this plan before, I will just be helpless. With counselling that I have had, I now see that sky is really limit for me as I can still do many things.

Counselling is a social factor that involves interaction between the patients and healthcare professionals, in which knowledge exchange on diagnosis, aetiology, treatment and other aspects of illness management takes place. Since counselling is free at the point of use, because it is part of the free ART programme, counselling is a social factor that is predicated on government policy, and has been instrumental in making the experience of continuity to be possible for the participant. Access to free counselling created an avenue for Moji to return to schooling and ensure that life continued as previously planned. Therefore, healthwork shaped by the government policy has helped the participant to utilise the opportunity offered by the counselling service to re-establish continuity in pursuing her previous biographical plan (of the past) and bring it to the fore in the new present. The social nature of counselling has facilitated the individualised practice of adherence, a component of healthwork that has enabled the participant to re-establish continuity, by gaining admission to the polytechnic where she intended to enrol for a bachelor programme.

Healthwork helped the participants to be realistic about the new present and move beyond the empty present or living in the past, those states that characterised the immediate post-diagnostic era. The period of nine years between the HIV disruption and when the continuity was achieved constituted an important phase in the biographical temporality of the participant. To Moji, healthwork enabled her to continue with her education plan after nine years. However, the time lag of nine years was not anticipated by the participant at the period of the diagnosis or when the disruption occurred, but she was certain that she would achieve continuity in her educational plan at a time in the future. It can be suggested that poverty or lack of financial means, which is a social condition, could have been responsible for her having to wait those nine years in her continuity quest. During this temporal epoch, the time and social circumstances of the participants have changed, as their biographies have undergone changes that required the actualisation of the previous plan to be undertaken under different temporal arrangements that the new present offered.

Apart from counselling, adherence was another component of healthwork that was central to the actualisation of the previous aborted plan because the aborted old educational plan was unachievable. Adherence enables Moji to have a healthy body, while counselling enables her to construct the required hope to move on with her life within the scope of the engagement offered by the new present. Both adherence and counselling ushered in a government policy, helped to alleviate the effect of the discontinuity associated with the aborted plan, and allowed the participant to go back in time and undertake a higher education programme (diploma) under new and different situations.

In the same way that healthwork aided the continuity of the education plan for Moji, it was instrumental in the establishment of a new marital relationship for Tossy, a 55-year-old woman living with HIV for six years:

> When I separated from my first husband, I was sad because I thought nobody will want to marry anyone living with HIV. For three years, I was not happy with myself and I still wanted my husband back. In the support group meetings, we were advised to marry within the support group, as it will help to deepening understanding between couples since they have similar conditions. Initially, I ignored it and never thought of having another husband. But now, I have remarried and have a child. However, my husband and I are both HIV-positive individuals and we both have two children each from previous relationships. So, life goes on like before when HIV never ensued. Now that I have five children, which are my future, I plan to raise them to adulthood together with my new husband. I know that if I continue using his medication according to instructions given at hospital, I will be able to achieve this plan in the future.

Support group participation is a social factor that shapes the experience of continuity in the marital relationship of the participant. Support group participation is a form of social factor, whose network of relationship it engenders has important implications on an individual’s decision making about having a new marital relationship. This component of healthwork, together with adherence, provided a fertile ground for a new marital relationship to ensue, and ensured that continuity in the biographical temporality of the participant, especially towards remarriage, takes place. These components of healthwork are social factors that allowed a new marital relationship to ensue, and enabled continuity to the disrupted marital relationship of the participant as a result of the window of opportunity offered by the new temporality (new present). For Tossy, the question of when to achieve continuity in her temporal experience did not arise until three years following HIV diagnosis. When the participant finally moved on to form a new marital relationship, she never anticipated a specific timeframe in which such a new marital relationship would ensue. Therefore, the question of when (precise timing) to start a new marital relationship is unpredictable. Nevertheless, the practices of healthwork helped the participant to restart and resume a new marital relationship in different circumstances from those in which she was diagnosed.

Whereas in Moji’s case it was adherence and counselling that were instrumental in fostering continuity in her education plans, in Tossy’s case adherence and support group participation were the components of healthwork that were pivotal in facilitating continuity in her marital relationship. The social relationship that stemmed from the support group participation created a new social circumstance and provided the participant with the incentive to gradually move away from the discontinuity associated with an aborted marital relationship and see what could be achieved within the confines of the new present in which she found herself. To the participant, the significance of adherence is that it prevents opportunistic infections that could take a huge toll on her body and inevitably prevent her from finding a good husband. Therefore, the practices of healthwork are shaped by social interaction and relationship, which enabled continuity to take place and ensure that the participant utilised the opportunity offered by the new present to achieve her previous biographical plan of having a settled family relationship with a new husband and two new children under different arrangements in the new present.

With the practices of healthwork, the participants were afforded the opportunity to reconstruct the aborted/discontinued marital relationship and ensure continuity, albeit in a slightly different temporal pattern. In this regard, healthwork initially ushered in stability for HIV-positive individuals with disrupted biographies, and later offered the continuity needed to bring the expectations of the past to fruition in the present, connecting the past and present with the future.

As healthwork was instrumental in fostering a new marital relationship for Tossy, it has enabled continuity in the travel plans of Hope (a 35-year-old woman living with HIV for six years) to take place. Although healthwork is an individualised practice that enabled Hope to restart her thwarted travel plans under different situations, it was greatly influenced by the social relationship inherent in participation in support group:

> When my Australian visa application was rejected due to health reasons (HIV), I was devastated beyond belief, and I forget about travelling abroad. For the next four years, I was not happy with the situation because I met all other criteria to be granted the visa. During one of our support group meetings, we were told we can achieve any plan regardless of our HIV condition. One day, I learnt that one of the support group executives nominated me to be part of the national executive of network of people living with HIV in Nigeria. Being part of the national executive has enabled me to travel to HIV conferences abroad. In fact, let me say on the lighter mood, there are some countries that I would not have travelled to if I were not HIV positive. To the glory of God, for the past few years I have had the opportunity to travel to some conferences abroad in Vienna (Austria), South Africa, Brazil, Thailand, India, Canada and some other African countries to represent Nigeria. Having HIV is one of the criteria for attending those conferences in which all expenses were paid on my behalf.

Participation in a support group was the key structural component of healthwork that fostered a new social relationship, which enabled the continuity of Hope's disrupted biographical plan (travel plans). After four years of disruption, the support group participation provided the necessary encouragement and hope that enabled the participant to achieve her thwarted travel plans under the different circumstances now afforded by the new present. For Hope, the question of when to restart the aborted travel plans and ensure continuity in her biographical temporality did not emanate from the participant's narratives. The plausible explanation for this is that the participant was not sure whether she would travel again or anticipate that she could travel to countries like Vienna (Austria), South Africa, Brazil, Thailand, India, and Canada at the time when HIV onset ensued. Like Moji, it could be that poverty and lack of financial means undermined her ability to achieve continuity in her travel plans immediately after diagnosis and delayed the biographical plan until an opportunity for such came. The participation in an HIV conference (which is free) allowed the participant to escape the reality of poverty and lack of financial means that had prevented the realisation of continuity in her biographical plans.

Regardless, this social factor inherent in support group participation helped to influence the continuity that the participant experienced, by reconstructing and rebuilding the disrupted plans of travelling and settling abroad through the opportunities to attend HIV conferences abroad. The practices of healthwork therefore allowed the participant to construct the hope and encouragement needed to move on with her life and achieved the previous aborted travel plans under new and different circumstances.

For all these participants, healthwork enabled continuity in their biographical temporalities, by facilitating the punctuated flow of orderliness between the past, present and the future. Therefore, adherence, counselling, and support group participation are the core elements of healthwork that were instrumental in making continuity possible. With continuity, these practices of healthwork, which are shaped and reshaped by the social processes and interactions implicit in doctor-patient relationship and peer network ties, enabled the participants to go back in time and pick up from where they left off when they were diagnosed, and allowed a re-orientation of biographical trajectories towards the new scope of engagement that the new present offers.

5.3.2 Positivity

Despite uncertainty about the future arising from concerns over the continuation of the ART programme in Nigeria, the therapeutic turn towards undetectability and non-infectiousness was the important social factor that shaped a sense of positivity about the future for the participants. For the participants, being positive means looking at the brighter side of undetectability and non-infectiousness and towards the imminent end of HIV, and having a positive frame of mind that a cure for HIV will override their fears and worries about the possible discontinuation of the ART programme in the future. Healthwork helps to deepen the sense of positivity associated with the current treatment regime, by enabling the participants to achieve undetectability in the best possible ways. Also, being positive about the undetectability turn is different from achieving undetectability, and healthwork was instrumental in helping the participants to achieve detectability, and thus deepen the sense of positivity offered by the undetectability turn. With healthwork, the participants believed that undetectability is achievable and possible.

Healthwork enabled Funmi (a 34-year-old woman living with HIV for three years) to navigate away from living in the uncertain future associated with fears over the continuation of the ART programme in Nigeria, by encouraging and giving the participants the confidence to embark on practices that can achieve a new regime of HIV undetectability and non-infectiousness:

> I believe a cure would soon be found and it will be based on those who are tested undetectable first. My intention is to reach that undetectability by taking my drugs daily, so that I will be part of the cure. If the cure is found today, we will campaign and put pressure on the government to get us the cure. I know they will not watch us die like that. I am excited by recent developments that reported undetectability. I believe cure will work for those who are tested undetectable, and I undergo testing anytime I visited hospital to know the state of my viral loads. Because my ambition is to attain undetectability, so that when the cure comes, I will be beneficiary of it.

The therapeutic shift towards undetectability brought hope to Funmi about the impending cure for HIV, as she had been worried about the future. Healthwork deepens the sense of positivity, by giving the participant the incentive to attain undetectability. This sense of positivity overrode her sense of uncertainty about the discontinuation of the ART programme in the future. Undetectability, facilitated by the social circumstance of undetectability turn, brought about a positivity, which Funmi shared and wanted to achieve. Although Funmi has not achieved undetectability, a sense of positivity around undetectability buoyed her hopes of a favourable future beyond the fear and worry posed by the possible discontinuation of the ART programme in Nigeria, leading to a lack of free drugs and an affordability problem. The quest towards attaining undetectability, especially through adherence and testing in the futuristic sense, provided a necessary hope to the participant to construct a sense of positivity that allayed her fears about the potential consequences that the discontinuation of the ART programme could cause in the future.

Unlike Funmi, who was aspiring towards undetectability, healthwork strengthens the sense of positivity experienced by Vicky (a 45-year-old woman living with HIV for 11 years), who had attained undetectability. The narrative of Vicky demonstrated how healthwork deepened the sense of positivity, as she became buoyed by the hope that undetectability and non-infectiousness could actively lead to a cure for HIV. This sense of positivity and hope outweighed her fear about the potential discontinuation of the ART programme:

> My last two viral load tests have shown undetectable. With this, I am elated that the cure is imminent. My concern is how to remain undetectable, and I am doing everything I could to remain undetectable. Even if this ART programme suddenly stopped, there will be no incentive for government to deny us if cure has been found. I believe if the cure is found and HIV has been eradicated in other parts of the world, there will be no pressure to eradicate it too in Nigeria.

The undetectability turn in the HIV therapeutic landscape created a sense of positivity for Vicky to construct hope about the cure for HIV, using undetectability and non-infectiousness as a counterweight to the uncertainty about the future of the ART programme. Healthwork (through adherence and testing) enabled this experience of positivity to be practicable in striving towards undetectability. To the participant, ending the ART programme pales into insignificance if a cure for HIV is found. Healthwork has changed the individual circumstances of the participants from the state of hopelessness (about a lack of HIV cure and future discontinuation of the free ART programme) to a state of being hopeful and positive about the future. Therefore, the concerns of the participant are now oriented towards the future of HIV, and less about the future of the ART programme. Achieving undetectability buoyed the hope of the participant about the future and created positivity in place of the uncertainty associated with the future cessation of the ART programme. By sustaining undetectability (possibly through adherence and testing), healthwork helped to deepen the sense of positivity that deconstructed the sense of living in the uncertain future.

Generally, healthwork plays a significant role in reconstructing the disrupted biographical temporality of the participants through continuity and positivity, as observed in this study. It was further revealed that adherence, testing, counselling, and support group participation are the important elements of healthwork that were utilised by the participants to foster continuity and deepen positivity in their respective reconstructions of disrupted biographical temporalities. Healthwork offers the stability that provides a springboard upon which continuity can occur or positivity can continue in the everyday lives of HIV-positive individuals.

5.4 Conclusion

This chapter has examined the impact of healthwork on the biographical time of people living with HIV, starting with an analysis of how HIV disrupts their biographical temporal orientations or sequences, and continuing with a description of how healthwork was instrumental in reconstructing their disrupted biographical temporality. An HIV diagnosis accelerated the awareness of temporality that had been taken for granted by these people before they were living with HIV. The sense of biographical time for people living with HIV is shaped by how the HIV diagnosis acquired a new significance and meaning in the temporal understanding of their past and present plans and their engagement with the new present. The findings in this chapter revealed that the temporal continuity, assumed to be orderly by the participants in their past lives, was disrupted by the onset of HIV in their present moment, and this disruption ushered the participants into the temporality of the new present.

There are three key findings of this chapter. The first finding is that HIV disrupted the biographical temporality of the participants, and the consequences of this disruption were expressed in the forms of uncertainty about the future, and discontinuity in relation to their career, travelling, marital relationships, and financial plans. This experience of discontinuity was facilitated by cultural influence and other social factors such as timing of diagnosis and financial constraints, the consequences of which were reflected in the participants' careers, marital relationships, and financial plans. This discontinuity eventually triggered nostalgia, in which the participants refused to fully live with the reality of the new present and refused to let go of their past lives. The social circumstances in which the participants had lived their past lives enabled the onset of HIV to foster a sense of nostalgia and caused them to live in the past.

Furthermore, it was also observed that HIV disruption brought uncertainty to the futuristic sense of the participants that was previously deemed to be safe and secure, and such uncertainty was the reflection of the social circumstances caused by the lack of credible alternatives to the future course of actions and events. The social factors that shaped the experience of uncertainty are lack of HIV cure, and the sustainability question around the continuation free ART programme in Nigeria. This finding is specific to the disruption of biographical temporal orientations for HIV-positive people in the Nigerian context.

The findings on how HIV disrupted the biographical temporalities of the participants, and ushered in discontinuity, share similarities with the work of Davies (1997) and Pierret (2001), Pierret (2007) in the contexts of living in the empty present. In this sense, it was the disruptive consequence of discontinuity that made the participants live in the empty present and withdraw from social interactions. The participants who experienced an empty present in those studies were those who did not reconcile the depth of the rift that opened in their everyday life by HIV infection with their present reality of living with HIV. The participants who experienced discontinuity in this study were nostalgic and were living in the past. Living in the past describes the participants' refusal to consider their new present as significant due to their inability to recover opportunities that were lost in the past. The consequence of this discontinuity was the experience of being nostalgic about the social relationship that formed the experience of past living. This culminated in making the new present to be lived in one of dissatisfaction and sadness, because of the inability to replicate the social relationship that defined the past and present that were destroyed and thwarted by HIV. Therefore, the observation of living in the empty present in previous studies aligns with the observation of living in the past in this study.

What seems to be fundamentally different between previous studies and my research is the observation that participants were living with an uncertain future following HIV diagnosis, which is in contrast with Pierret's (2001) observation that HIV-positive individuals are living with a possible future. The uncertainty associated with the future of the free ART programme in Nigeria made participants in this study live in the uncertain future, and they are not preparing for the future. In Pierret's research, however, living with a possible future is the experience of participants who regarded the past as gone, but believed that their future would be great, and therefore they are consciously preparing for future possibilities.

Secondly, the theme of uncertainty—as the disruptive consequence of HIV diagnosis in this study—widely connects with the constructions and experiences of biographical temporality in the broader literature on living with HIV, especially on uncertainty. This is because participants in the pre-HAART era experienced and faced greater uncertainty than other ill persons in predicting how their illness would affect their lives (Weitz 1989). This uncertainty stemmed from the nature of the medications available in the pre-HAART era. However, uncertainty in the HAART era is no more prevalent among persons living with HIV than among those who suffer from many other illnesses, because the therapeutic breakthrough of HAART transformed HIV from a terminal disease into a chronic illness (Palmisano & Vella 2011) and improved life expectancy for people living with HIV. The therapeutic landscape of HAART removed the uncertainty associated with the everyday life of people living with HIV. Since HIV does not yet have a cure, and its treatment is expensive without medicines that are subsidised or provided free by the state, the participants in this study experienced and faced uncertainty (uncertain future) similar to that faced by the participants in the pre-HAART era. They held the fear and concern that the current regime in Nigeria of free antiretroviral drugs for people living with HIV might be unsustainable and could be stopped in the future. The discontinuation of free drugs in the future would have devastating health consequences for HIV-positive individuals, who would experience the problem of affordability for expensive medications. However, the uncertainty in both pre-HAART and HAART epochs, as revealed in this study and previous research, stemmed from the social circumstances caused by the lack of credible alternatives to the future course of actions and events. The experience of uncertainty as the disruptive consequence of the biographical temporality in HIV-positive individuals, therefore, reveals a wide array of personal, social, and structural issues that are widely connected to the everyday management of HIV.

The final finding revolves around the importance of adherence, testing, counselling, and support group participation as key elements of healthwork in the reconstruction of the disrupted biographical temporalities of the participants. The utilisation of these components of healthwork shows that the biographical work articulated by Corbin and Strauss (1987; 1988) to reconstruct disrupted biographies—and, by extension, biographical time—cannot be undertaken without the help of actions and activities that are within and outside the normal daily routine of the participants, which healthwork symbolises. The reconstruction of the disrupted biographical plans of the participants are facilitated by healthwork through continuity and positivity.

Through continuity, healthwork enabled HIV-positive individuals to reconstruct their disrupted biographical temporalities, and allowed them to continue the aborted present engagement under new and different circumstances. The social factor that shaped the experience of continuity for the participants was the changes in government policies towards HIV/AIDS. Also, healthwork deepened the sense of positivity created by the current treatment regime towards undetectability turn, by enabling the participants to achieve undetectability in the best possible ways. With healthwork, the participants believed that undetectability was achievable and possible, and thus deepened the sense of positivity needed to navigate away from living in the uncertain future associated with potential discontinuation of the ART programme.

These findings address the central focus in this chapter, which is the lack of engagement in the sociological literature regarding the impact of healthwork on the reconstruction of disrupted biographical temporality. The findings have helped to address the gap of how to reconstruct disrupted biographical time and the role that healthwork plays in this process. This has not been addressed in Corbin and Strauss' (1987; 1988) studies on biographical work, or that of Mykhalovskiy et al. on healthwork (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008). Conclusively, the crucial importance of healthwork for the reconstruction of disrupted biographical time is significant to HIV management, as it was instrumental in enabling HIV-positive individuals to reconstruct biographical plans and forge a new present that is relevant to their health and everyday lives.

One of the most important implications of analysing the construction of biographical time is that it involves the construction of the body in the HIV context. The disruption and reconstruction of biographical temporalities are undertaken by the embodied actions and through the body. Thus, by narrating about the experience of past, present and future, the participants are situating their embodiment as the centrality of such reconstruction. The understanding of biographical time is incomplete without an understanding of how the body is constructed. Therefore, understanding the impact of healthwork in the reconstruction of disrupted biographies cannot be fully understood without understanding the impact of healthwork on the body and the corporeality that revolves around HIV infectiousness/non-infectiousness. This will be explored in the next chapter.

CHAPTER SIX

THE BODY, CORPOREALITY AND HEALTHWORK

6.1 Introduction

The previous chapter focused on exploring the impact of healthwork on biographical time, with respect to how biographical time was disrupted following the onset of HIV and its reconstruction through healthwork. However, this chapter seeks to explore the impacts of healthwork on the corporeal construction of HIV non-infectiousness in everyday life and how HIV-positive people construct their corporealities of infectiousness and non-infectiousness following the onset of HIV, especially in the HAART era. In exploring these questions, two issues are central to the analysis of healthwork in this chapter.

The first is the notion of the body. The body is a biological, material, and physical entity that consists of such features as muscles, flesh, bones and blood, and contains specific capacities which identify us as humans (Shilling 2003: 11). The body as a ‘physical component of human agents’ (Shilling 2003: 77) is mediated by biological needs and shaped by social circumstances in which we live as humans. The body in this regard is not outside the human agents, rather we engage with the body as the location at which human ‘being’ is situated. The body, therefore, constitutes the basis of our being-in-the-world—where we experience pain and suffering, making a difference in the world, intervening in social situations through ‘our bodily emotions, preferences, sensory capacities, and actions’ (Shilling 2003: ix) that constitute the fundamental essence of our social forms and beings. As human beings, ‘we cannot perceive anything, and our sense cannot function independently of our bodies’ (Nettleton 2006: 114).

Therefore, the body is framed around corporeality (Crossley 1995b) especially in this chapter, which means our bodies are not simply biological and physical components, but social phenomenon that are embodied. Without our bodies, we do not exist as humans (Crossley 1995a; Howson & Inglis 2001; Williams 2003; James & Hockey 2007), and it is through the body that we experience different forms of embodied actions like thinking, speaking, sleeping, eating, experiencing illness, and medication use.

Being human, we often take the body for granted in everyday life, but when illness, accident and impairment ensues, ‘people become conscious of their body and reflect upon them in ways that may or may not be on their own terms’ (Charmaz & Rosenfeld 2006: 35). In other words, a new sense of corporeality is forged following the onset of a chronic illness. Whenever an illness condition ensues, the ill person assumes a new corporeality that is different from the old corporeality. This is because the corporeality that we appropriate following the onset of illness is different to the corporeality that we assume prior to illness. In an HIV context, when an individual is diagnosed with HIV, he/she assumes or appropriates the new corporeality following the acceptance of the viral condition as someone as having an HIV body. In other words, the HIV body means that there is a new corporeality that is different from the old corporeality that was assumed prior to HIV diagnosis. This new corporeality of HIV body has been regarded as the HIV body-in-themself (see Chapter Two for more details). This new corporeality of HIV body-in-themself is predicated upon the social meanings and cultural understanding of HIV in different contexts and settings. Sociological studies have examined how individuals assume different corporealities due to the circumstances and contexts they find themselves (Crossley 1995a; 1995b; Csordas 1995; Shilling 2001; Howson & Inglis 2001; Williams 2003; James & Hockey 2007), but the dimension in which the corporeality of HIV body-in-themself is assumed in the Nigerian context has been identified as a gap to be explored in Chapter Two. This is the empirical question that will be explored in this chapter.

The second issue is the notion of non-infectiousness. The nascent trajectory of HIV body from infectiousness to non-infectiousness has generated a great deal of attention in popular culture, media, academia, and clinical and health settings following the publication of a Swiss statement (Adam 2011). In 2008, a group of Swiss HIV experts published the Swiss Consensus Statement and claimed that ‘an HIV-infected person on antiretroviral therapy with: undetectable viral load for at least six months; have no other sexually transmitted infections, couple with effective adherence to antiretroviral therapy is not sexually infectious, that is, cannot transmit HIV through sexual contact’ (Vernazza et al. 2008; Vernazza 2009). Despite its rejection on the grounds that it was not based on clinical trials, but rather on an observational study (Young et al. 2019), recent studies seemed to have validated the claims made in the Swiss Consensus Statement (Attia et al. 2009; Donnell et al. 2010; Cohen et al. 2013). The publication of the Swiss Consensus Statement reignited a new sense of hope and changed our understanding about the use of pharmaceuticals to prevent HIV non-infectiousness and global policy on HIV prevention (Young et al. 2019). The implication of the Swiss Consensus Statement on HIV management is the shifting of cultural narratives from an infectious body to a non-infectious body as far as HIV-positive body is concerned.

This shift towards a non-infectious body, which the Swiss Consensus Statement argued, has developed into debates, theoretical and empirical engagements in which sociologists and other social scientists paid significant interest. Sociological studies exploring the corporeal issues surrounding the HIV infectious/non-infectious are limited, but notable studies were undertaken by Asha Persson in Australia (Persson 2011; 2013). Central to Persson's studies is the idea that 'antiretroviral treatments are increasingly considered so effective at viral suppression that they render people with HIV sexually non-infectious' (Persson 2013: 1065). Following Squire's (2010) notion of naturalisation and normalisation, Persson argued that antiretroviral therapy has ushered in the non-infectious body. In furtherance of this argument, Persson noted that HIV treatments are not only effective and efficient in enhancing the survival, health and life quality of people with HIV, but are capable of reducing the amount of the virus to undetectable levels in the blood, and thereby reducing the risk of HIV transmission.

What seemed to be a shortcoming associated with the discourse on HIV non-infectiousness is the reduction of non-infectious body to adherence, and this constitutes a limitation in the sociological debate. Much of the debate about HIV non-infectiousness appears to be limited solely to adherence to antiretroviral treatment, whereas there are more actions and practices that people living with HIV undertake (including adherence) to achieve non-infectiousness corporeality, which healthwork represents. Therefore, the question of how a corporeal sense of HIV non-infectiousness is shaped by the healthwork of HIV-positive people in everyday life has not been explored, and this constitutes a gap in sociological literature on HIV non-infectiousness.

This chapter addresses these gaps by exploring how HIV-positive individuals construct the dimension of the corporeality of HIV body-in-themself, as discussed in section 6.2. In section 6.3, the questions of how HIV-positive individuals construct their corporealities of HIV bodies around non-infectiousness, and how a corporeal sense of HIV non-infectiousness is shaped by the healthwork of HIV-positive people in everyday life, were explored and discussed. Lastly, in section 6.4, the conclusion, and implications of the findings in the chapter, are discussed.

6.2 The HIV body and the lay construction of corporeality

Being diagnosed with HIV inevitably facilitates the corporeality of HIV body. The acceptance or rejection of a new corporeal reality may depend on some factors such as scientific knowledge of HIV, the cultural perception of HIV, and the personal circumstances of the patients involved. Nevertheless, how HIV-positive individuals construct their new corporealities of HIV bodies-in-themselves is contingent on how they understand the consequences of HIV on their embodied agency. In this study, three categories of how the dimensions of the corporeality of HIV body-in-themself were constructed were observed: otherness, dirty body, and infectious body. These categories are discussed in turn.

6.2.1 Otherness

The notion of otherness is central to a sociological understanding of how minority and majority identities are constructed in society (Gilroy 1991; Frankenberg 1993; Hall 1997; Calcutt, Woodward & Skrbis 2009; Gabb 2011). Every society, as Kastoryano (2010) noted, has its otherness, as a majority often considers a minority as ‘others’ based on a divergence in beliefs, cultures and values, and in race, gender, ethnicity, sexuality, social class and health conditions (Sampson 1993; Walby 1996; Reicher & Hopkins 2001; Petersoo 2007). The implication of otherness is the creation of an ‘in-group’ (a group that the majority belongs to) and an ‘out-group’ (a group that a minority belongs to or a group that the majority do not belong to) (Staszak 2008: 1). An ‘out-group’ is a negative categorisation of minorities by the majorities because the former does not share what the latter represents. For instance, gay, lesbian and disabled people are categorised as ‘others’ or ‘an out-group’ by the majority who are heterosexual and able-bodied. In an HIV context, people living with HIV are historically stigmatised and discriminated as ‘others’ and an ‘out-group’ in both Western and non-Western societies.

Throughout the 1980s, there was a public health concern, moral panic, negative stereotyping and intense ‘public reactions to persons presumed to be infected by HIV’ (Herek & Glunt 1988) in affected Western countries. In a non-Western context, especially Nigeria, the cultural understanding of HIV is that it is a disease that emanates from promiscuity and an adulterous way of living. In this sense, HIV-positive individuals in Nigeria are categorised as belonging to others—because they belong to the group of people who live wayward, promiscuous, and adulterous lifestyles (Tocco 2010). HIV-positive individuals are part of the out-groups due to their viral condition.

Otherness is a cultural schema created by the majority in Nigerian society based on the cultural understanding of HIV. Otherness is activated when the HIV body constitutes the site of discrimination, labelling, and stigmatisation. Having HIV is therefore tantamount to being associated with ‘otherness’, as nine participants reported how they constructed their HIV corporealities following the diagnosis and onset of HIV. The corporeality around otherness is the enactment of HIV body-in-themself, in which the participants appropriate the cultural narratives of HIV and that forms the basis of their corporealities following HIV diagnosis. With HIV body-in-themself, their construction or expression of otherness is thus being defined by enacted stigma.

HIV corporeality for Funmi (a 34-year-old-woman who has been living with HIV for three years) represents how otherness is constructed based on HIV body:

> To be sincere, HIV is a painful something. In fact, I don’t know how to say it. The moment I thought about HIV in my body, I feel dejected. I’m ashamed to say I have HIV publicly because people will say I’m now part of those that are promiscuous and adulterous. Having HIV does not give me the voice to publicly disclose my condition (HIV-positive status). It does not allow me to openly disclose the type of drugs that I’m taking and its efficacies. It seems as if I’m in another world.

With otherness, the corporeality of HIV body-in-themself is constructed and expressed as reactions to the cultural inscription of HIV, which structured the imaginaries of the body within certain patterns of intra-corporeal encounter, despite not been exposed to the cultural gaze. The corporeal categorisation of otherness emanated from the participant’s experience of a felt stigma rather than experiencing such otherness through enacted stigma. The cultural understanding of HIV has been internalised by the participant, and thus caused the feeling of otherness to stem from the society, even when it was not a result of enacted stigma.

Unlike Funmi, whose corporeality of otherness is the expressivity of felt stigma, the corporeality of HIV body-in-themself for Omooba (a 57-year-old man who has been living with HIV for 30 years) is the expressivity of enacted stigma corporeality, in which HIV body became the marker of otherness:

> When I was diagnosed with HIV, my immediate response was to free myself from any guilt or shame of having HIV by declaring my HIV-positive status publicly. As my friends were aware of my HIV status, they avoided me like plague. Even when I see some of them in the public space, they often hide themselves from me or deliberately ignore me when they cannot hide. Having disclosed my HIV status on television and radio with the state government, I became part of those that are being avoided in the society. Sometimes, I do not care, and sometimes I feel sad about it.

The construction of otherness was conditioned by a cultural gaze in which meaningful reality of having HIV is shaped through cultural systems of typification/gaze and invoked through an interpretive encounter. The participant’s sense of otherness is the expression of being othered from the rest of the society. Otherness, which was the consequences of HIV disclosure, became part of the corporeality of HIV body-in-themself that comes with having HIV. The construction of otherness is the corporeality of HIV body-in-themself, that is located within cultural, moral, and social universes. With otherness, the enactment and expression of corporeality around HIV body-in-themself occurs when the participant appropriates cultural understanding of HIV in his reaction to having an HIV body. In this sense, the cultural inscription of having HIV bodies could shape the participants’ reactions to HIV diagnosis, and be capable of defining and shaping the everyday life of the participant. Although adherence might be central to the participants’ ability to conceal their conditions, concealment and maintaining secrecy around HIV positivity is the key priority for the participants, alongside other components like testing, counselling, and others.

Generally, the participants’ construction of otherness revolved around the corporeality of HIV body-in-themself, which is expressed through felt stigma but defined by the enacted stigma. What is central to this corporeality is hinged on the body as the marker of cultural construction of otherness in Nigerian society. From the participants’ narratives, it can be revealed that concealment is one of the prioritised components of healthwork that HIV-positive individuals with corporeality of otherness undertake around their conditions in everyday life.

6.2.2 Dirty body

Twelve of the participants constructed their corporeality of HIV body around dirty body. The corporeality of HIV body as dirty body is forged by the participants through an entrenched religious understanding of HIV in Nigeria. Like the corporeality of ‘otherness’ that is shaped by cultural schema, the corporeal construction of dirty body is rooted in religious schemata, where HIV is linked with impurity, uncleanliness and contamination associated with spiritual pollution.

In Nigeria, the religious inscription of the HIV body connotes a product of spiritual pollution and immorality that manifested from promiscuous, adulterous, and sinful sexual practices (Aguwa 2010). In fact, the two dominant religions in Nigeria—Christianity and Islam—affirmed that HIV/AIDS was divine punishment to those who live wayward and unrighteous lifestyles with their body (Aguwa 2010; Smith & Mbakwem 2010; Tocco 2010). The corporeality of dirty body is the expressivity of HIV body-in-themself in which participants embody and enact a social structure by way of their actions. With dirty body, the participants’ construction of their corporealities is mediated by how the gaze of social structures (religious stigmata) shape the matrices of concrete human interaction as they unfold through intra-corporeal encounters. Following the diagnosis and onset of HIV, participants, especially Nike (a 39-year-old-woman, living with HIV for eight years), deployed the trope of dirty body to construct their corporealities around the presence of impurity and infection:

> As humans, we have our weaknesses, and there is no way you will not feel bad if you are told that you are HIV positive. I felt dejected and dirty because the virus is in my body. Having the virus means that I was contaminated, and I was very sad about this. In fact, for a few weeks I could not go to church because I felt dirty.

The participant’s embodiment of a dirty body is the feeling of being contaminated with uncleanliness, which HIV depicts in a religious representation. With dirty body, the corporeal expression of HIV body-in-themself, which the participant constructed, is the demonstration of corporeality in structures and structures in corporeality. This corporeality of dirty body, as expressive and responsive to religious inclination, carries an aura of salience that is immediately experienced and structured within the imaginaries of the body.

The religious basis on which a participant’s corporeality of a dirty body was located, serves as the tangible and concrete expression, or manifestation, of corporeality that is being defined by enacted stigma, which participants had appropriated and inculcated over time. Resorting to spirituality, however, seems to be the most prioritised form of healthwork that participants in this category engage as a response to HIV diagnosis. In fact, when asked about their initial response after been told about HIV positivity, one of the participants (Menty) commented:

> I first accepted Jesus into my life as my Saviour and repented of my wayward ways and sinful lifestyle. I know that with God everything is possible. Then, I avoid taking alcohol or engage in risky behaviours that can undermine my health.

Spirituality takes an important priority, even though adherence is central to the ability to practise spirituality. Nevertheless, spirituality was prioritised by the participants before other forms of healthwork, even though other components of healthwork are undertaken by the participants simultaneously. This enables the participants to utilise spirituality to remove the guilt and moral shame associated with HIV, in which the corporeality of the dirty body depicts.

6.2.3 Infectious body

HIV diagnosis confirms not only the presence of a virus but generates a corporeality that affirms that they are carriers of a contagious and infectious body. The corporeality of an infectious body stems from the biomedical explanation that HIV is an infectious disease that can be transmitted to other people through blood, vaginal fluid, semen, breast milk and anal mucus (Synnott 1993). The corporeality of infectious bodies is the expressivity of HIV body-in-themself in the everyday life of the participants. The biological facts rooted in biomedical explanations is orchestrated by the occupation structure of the healthcare profession. In this regard, the HIV body has been exposed to the gaze of the social structure, but has not been defined by enacted stigma, as observed in otherness and dirty body above. This biomedical explanation shapes how HIV-positive individuals understand their bodies following HIV diagnosis. Eleven participants described their HIV body around the corporeality of an infectious body based on the biomedical explanation available to them. The narrative of Tossy (a 55-year-old-woman, living with HIV for six years) illustrated how the corporeality of an infectious body was forged:

> Immediately I realised that my body was infected with HIV, the first adjustment that I made was that I decided not to remarry because I do not want to infect others or be reinfected. The second thing that I did was that I separated my belongings from my children. I got my own hair products and I don't want to share any of it with my daughter because I don't want to infect her, and I don't share many things with others.

With infectious body, the corporeality of HIV body-in-themself that the participant constructed demonstrated how the contagious construction of disease explanation, rooted in the biological facts, found its expression in the biomedical branding of HIV as a disease that can be transmitted through sexual intercourse (vis-à-vis-remarriage) and other practices like sharing in which blood exchange can be initiated. Unlike the corporeality of otherness and dirty body that were shaped by cultural and religious schemata, the corporeal construction of an infectious body is rooted in the biomedical model of disease and illness, where HIV is a contagious disease, and participants' sense of corporeality is oriented towards becoming infectious towards others, following the feeling that their bodies have been infected with the disease. Therefore, HIV body is a 'biomedical' fact that has infectious corporeal connotations.

Adherence and testing are the most prioritised forms of healthwork that participants for this study would undertake as a response to infectious corporeality. The narrative of Yemmy (a 47-year-old-woman, who has been living with HIV for 12 years) demonstrated this more profoundly by stating the following:

> When the reality was done on me that I got an infectious disease in my body, I take my drugs daily to prevent opportunistic infections and constantly attend quarterly medical check-ups to know the progression of the virus in my body.

The participant accepted the biomedical discourse of infectious corporeality, which depicts that they are now carriers of a contagious disease, and that, as a response to having an infectious body, adherence helps to contain the spread of the virus in the body, while testing helps to know how well the treatment is working and enables

HIV-positive individuals to know whether the level of the virus in the body is increasing or decreasing. These components of healthwork have saved countless lives and constituted the most effective way of managing HIV from developing into full-blown AIDS, and from spreading the virus to others, if their viral loads showed to be undetectable.

Generally, the corporeality of having an HIV body is constructed around HIV body-in-themself, which is expressed in three key categories: otherness, dirty body, and infectious body. These corporeal constructions are drawn from cultural, religious, and biomedical understandings of HIV, which demonstrated what corporeality was for people living with HIV following the diagnosis and onset of HIV. However, the components of healthwork like adherence, concealment, and spirituality that participants effectively deployed were the responses to these constructions of HIV corporealities in this study.

6.3 From Infectious body to non-infectious corporeality

In a conventional sense, the onset of HIV alters not only an un-infectious sense of corporeality but transforms un-infectious to infectious corporeality in a post-HIV diagnosis. In this sense, the onset of HIV, as Squire (2010) noted, denaturalises HIV-positive people as ‘other’ citizens based on biological, political, and social relations. Squire’s notion of naturalisation helps to unpack the twin processes of biomedicalisation and normalisation that are central to the shifting trajectories of HIV from an infectious corporeality to a non-infectious corporeality in recent times. Biomedicalisation is the transformation of infectious HIV bodies into non-infectious bodies through recent therapeutic advances in antiretroviral therapy (Keogh 2017).

With biomedicalisation, antiretroviral treatments are now effective in viral suppression and are making HIV-positive individuals sexually non-infectious (Persson 2013). Biomedicalisation, therefore, helps to foster normalisation; that is, turning people living with HIV from being contagious and an infectious ‘other’ into normal, de-stigmatised, ‘regular and unremarkable citizens just like anyone else’ (Squire 2010: 407) through efficacious antiretroviral treatment. This implies that effective HIV treatment can prevent HIV transmission through unprotected sexual intercourse. These notions of biomedicalisation and normalisation were further exemplified in the recent Swiss Consensus Statement, which marked or kickstarted a significant trajectory of an infectious body to an HIV non-infectiousness. The key argument in the HIV non-infectiousness debate orchestrated by the Swiss Consensus Statement is normalisation, which biomedicalisation of HIV prevention fosters for the people living with HIV in everyday life.

The implication of the Swiss Consensus Statement in normalising HIV is the shifting understanding from an infectious body to a non-infectious body in which HIV body-in-themself is re-imagined in a new corporeal light. Informed by normalisation, the Swiss Consensus Statement, together with the global mantra of treatment-as-prevention, facilitated a re-imagining of corporeality in the discursive framing of HIV-positive body. This study, however, has responded to this claim by further examining whether antiretroviral therapy has indeed fostered normalisation in preventing HIV non-infectiousness in a non-Western context such as Nigeria.

Infectiousness is a biomedical fact that has defined the corporeality of HIV body-in-themself following HIV diagnosis. In exploring the nascent debate of HIV body from infectious to non-infectious in the Nigerian context, it was observed that all the participants were aware of the argument proposed in the Swiss Consensus Statement and the impact of antiretroviral treatment in the medicalisation of HIV prevention. However, in exploring one of the research questions stated at the beginning of this chapter, which is to understand how HIV-positive individuals construct a non-infectious corporeality, it was further observed that participants constructed their corporealities of HIV non-infectiousness around two categories/themes: normalised body and partially normalise body. These corporeal constructions, which revealed that antiretroviral therapy does not totally offer normalisation, are the embodied experiences that were not only central to participants’ perceptions of HIV non-infectiousness, but also to the impact or risk that non-infectiousness posed to their sexual relations and other social practices, and their ethical and social implications. The sub-section to follow will now focus on how participants discussed each of these themes in turn.

6.3.1 Normalised body

The participants’ narratives of HIV non-infectiousness are framed around the normalisation of HIV body within the context of antiretroviral treatment. With the normalised body, the participants reported that antiretroviral treatment enables HIV-positive individuals to undertake normal activities like the rest of society. The corporeality of normalised body is the expressivity of HIV body-in-themself, in which HIV body is experienced and re-imagined as a normalised entity in the wake of effective antiretroviral treatment. Eleven participants in this category agreed that antiretroviral treatment ushered normalisation, and they therefore constructed their corporeality of HIV non-infectiousness based on their experiences and that of their colleagues in the support groups. Antiretroviral treatment has resulted in an HIV non-infectiousness body for Flakky (a 38-year-old-woman who has been living with HIV for 10 years) and culminated in HIV negative for her husband for the past eight years:

> My husband has been negative and un-infectious for more than 10 years that I have been diagnosed with HIV. This is because my viral load has been showing as being undetectable for the last eight years. In fact, my last viral load test shows less than 20, the result which I got this month (February 2018) because we used to undergo viral load tests every six months. What I can say is that the virus is still in the blood, but if the virus is less than 20, the viral load test will not be able to detect it because the test will not be able to know the specific result whether it is 15 or 17, and that is why it will show less than 20. At times, if I am tired of condom, I often had unprotected sex with my husband, and he is still negative as of last month when he went for a test. Before HIV, I had a child, and now I have two more and none of them is having HIV in their body. If I stop taking my medication, there is a tendency that my husband will be infected, but if I do not stop taking my medication, my husband will not be infected despite having unprotected sex.

The participant's understanding of HIV non-infectiousness was constructed around the corporeality of HIV undetectability which antiretroviral treatment has helped to foster and normalise. From the participant's narrative, the expressivity of HIV body-in-themself is shaped by the effectiveness of antiretroviral treatment in fostering normalisation in the participant in three contexts. These contexts include the following: the opportunity for the participant to be HIV non-infectious for eight years; ability to have two HIV-negative children; and keeping her husband un-infectious despite having unprotected sex. This corporeal construction of the participant, which was drawn from her experiences, became the yardstick for understanding what an HIV non-infectious body means to people living with HIV. Without imprimatur of healthwork, especially adherence and testing, the participant would not have achieved normalisation in her construction of HIV non-infectiousness.

In a different circumstance to Flakky, the narrative of Hope (a 35-year-woman, living with HIV for six years) helped to deepen the understanding of how antiretroviral treatment facilitated a normalised body in the context of childbirth in the Nigerian setting:

> When I was told about my HIV-positive status, the fear that I got then was how to conceive and have my own children. During a support group meeting, I was advised on how to go about it. Today, I have two kids. If not for the drugs, I do not think I would have been pregnant, not to talk of having children, and it would have been a shame and taboo in my community because nobody in my family is incapable of having children.

Childbirth in Nigeria is an essential activity because of the stigma associated with childlessness, barrenness, and infertility (Ibisomi & Mudege 2013). In a context like Nigeria, where fertility is highly valued, childlessness is not embraced culturally and socially (Bamidele & Pelumi 2017) and it has significant social and psychological consequences such as taboo, public contempt, and loss of an elderly status for the affected individuals (Olu-Pearce 1999; Ola 2009). Therefore, the cultural context of having children and the stigma around childlessness have made childbirth an essential practice in Nigeria. The use of antiretroviral treatment has enabled Hope to be pregnant and have two HIV-negative children, by normalising the body to perform the essential practice of childbirth. The corporeal nature of HIV body-in-themself constructed around HIV non-infectiousness was based on the normalisation effects that antiretroviral treatment had in suppressing the amount of HIV in the body to give birth to HIV-negative children. Like Flakky, the role of healthwork, especially adherence, testing and support group participation, enabled HIV non-infectiousness, as well as having children. In fact, without these components of healthwork, achieving these feats (HIV non-infectiousness and having children) would have been totally unrealistic.

Generally, the narratives of the participants in this category have further reinforced the observation of Squire (2010), Persson (2013), and Mazanderani and Paparini (2015) that antiretroviral treatment ushered normalisation that is rooted in the heart of HIV non-infectiousness. More so, the participants' observations have further consolidated the submission of Mykhalovskiy (2010), that HIV treatment has achieved more than its original aim of health maintenance, improvement, and survival. Without healthwork, achieving this original aim would have been impossible.

6.3.2 Partially normalised body

The corporeal construction of HIV non-infectiousness was based on the partially normalised body that antiretroviral treatment was able to foster in social practice. The participants accepted HIV undetectability as the key ingredient for HIV non-infectiousness to take place, but were concerned that, in some cases, HIV non-infectiousness is not a guarantee for HIV transmission not to take place. The expression of concerns and doubts about the inability to attain full normalisation is mediated by corporeal imaginaries, which inform the ways in which HIV body-in-themself is caught in the web of limitation inherent in the biomedical treatment of the HIV body.

Thirteen of the participants disagreed that antiretroviral treatment aided normalisation of HIV non-infectiousness; rather, they reported that antiretroviral treatment aided partial normalisation. In this regard, the participants in this category questioned the key premise of HIV non-infectiousness—that normalisation was central to the non-infectiousness debate spearheaded by the Swiss Consensus Statement. This questioning stemmed from the inability of normalisation to account for some issues that are strategic to the everyday practice of the participants. For instance, Menty (a 43-year-old man, who has been living with HIV for 11 years) constructed the corporeality of HIV non-infectiousness around partially normalised body by contesting the inability of HIV non-infectiousness to prevent HIV transmission in the context of blood transfusions:

> Undetectable does not mean non-infectiousness. This is because the HIV-positive person still has the virus despite being undetected. It is because the person's immunity is still very strong that is why it is undetectable. Someone whose HIV result shows non-infectiousness will not be able to donate blood to others. Like my own case, I went to hospital and I saw someone who needed a blood transfusion, I could not help because I am a carrier of HIV. Even if my HIV viral load test shows undetectability, I cannot donate blood because the virus is still in my blood and HIV will be transmitted to the recipient of my blood, if given.

Despite affording HIV undetectability, antiretroviral treatment cannot foster HIV non-infectiousness in the context of blood transfusions. The participant's narrative revealed that normalisation that antiretroviral treatment ushered in HIV non-infectiousness is not applicable for blood transfusions. In other words, the body is not normalised at all in the context of blood transfusions, so only a partial normalisation overall is possible for this participant. As HIV is still present in the body, despite its undetectability, the corporeal sense of HIV body is constructed around the partially normalised body. In furtherance to the partial nature of normalisation in HIV non-infectiousness, another participant, Joy (a 39-year-old woman, living with HIV for 12 years), commented in the context of organ donation and transplant:

> HIV non-infectiousness is not suitable when it comes to organ transplant. In the case of transplants from one person to another, such persons must undergo screening to confirm if he or she is fit. When I say fit, the person is not HIV-positive aside other diseases and illnesses the person might have. Screening may be carried out to find such an investigation, so if such a person who wants to do the donation is HIV-positive, if such a kidney is given or transplanted to that person, such a person can be infected with HIV.

In the participant's narrative, HIV undetectability and non-infectiousness are not relevant in the context of organ donation and transplant. Therefore, the normalisation that antiretroviral treatment brings is not applicable in organ donation and transplant. Normalisation is thus partial and oriented towards a single mode of HIV transmission, which is through sexual intercourse and breastfeeding, and not towards organ donation and transplant, as observed in the case above. Even in sexual practice, Lara (a 39-year-old woman, who has been living with HIV for six years) reported that normalisation is rather partial:

> The virus (HIV) is still there in the body. For the fact that it is undetectable does not mean that the virus cannot be transmitted to others. For instance, when I want to have a baby, there was a time I was asked not to use a condom with my husband. In fact, anybody undergoing PMCT [prevention-of-mother-to-child-transmission], the doctor and nurses would be monitoring the situation to ensure that the baby is not infected. They (doctor and nurses) will tell me when to have unprotected sex with my husband and when not to have unprotected sex. This is because they know that the virus is still there even when it has been suppressed through high immunity in the body. They will also tell us when to breastfeed the baby and when to stop breastfeeding. This shows that even with pregnant women undergoing PMCT, HIV undetectability is not completely non-infectiousness because of the risk and uncertainty involved.

By questioning HIV non-infectiousness, the participant's narrative underscores the limitation of normalisation implicit in the HIV non-infectiousness debate, within the context of breastfeeding and sexual practices in everyday life. The participant's narrative revealed that the normalisation of HIV non-infectiousness is only restricted towards limited sexual practice and breastfeeding, which are widely connected to maternal issues, and not everyday practices of people living with the HIV. The construction of HIV non-infectiousness in the participant's account hinges on the limit imposed on the applicability of normalisation in accounting for personal and sexual circumstances, in which the partially normalised body became the key corporeal reality. In other words, the participants in this category disagree with general beliefs that antiretroviral treatment fully normalises HIV and renders the body to be non-infectious. Rather, the participants reported that antiretroviral treatment partially normalises the body and renders it non-infectious in a limited context, as the normalisation notion is unable to account for a different set of circumstances like continuous breastfeeding, blood transfusion, organ donation/transplant, and daily sexual practice. The expressivity of HIV body-in-themself emanates in the questioning of undetectability and non-infectiousness, and this afforded the participants the opportunity to shift their understanding of HIV corporealities from normalisation to partial normalisation. The partial success recorded in normalising HIV non-infectiousness, as participants in this category reported, would not have happened if elements of healthwork like adherence, testing, and counselling are not involved. Therefore, healthwork has an important role to play if HIV non-infectiousness is to be achieved.

However, the central issue that emanated from the participants' constructions of corporealities of non-infectiousness around normalised and partially normalised body is the *undetectability as related to cure*. The more HIV-positive individuals aspire to attain HIV undetectability, the more they believe they are closer to a cure. This depicts that attaining undetectability is not a functional cure, but there is high hope and expectations from the participants that undetectability is going to facilitate a cure. This narrative, that effective antiretroviral treatment could foster normalisation and partial normalisation, could be located within the framework of expectations about biomedical treatment, situated in the sociology of expectations in science and technology (Brown 2003; Brown & Michael 2003; Hedgecoe 2003; 2004; Hedgecoe & Martin 2003; Hopkins et al. 2006; Hackett et al. 2007; Hedgecoe & Martin 2007; Pieri 2009). In the sociology of expectation, hyped visions of the technology are orchestrated to provide momentum to innovation projects. The drivers of expectation in sociological discourse are the technology company (pharmaceutical industry in this case), scientists, researchers and innovators where hype of a new technology is constructed through the narrative pathway (Brown 2003). The drivers of expectation in this study are the participants, whose expectations of antiretroviral therapy in fostering cure is the creation of a new reality that tends to overestimate the practical capabilities of biomedical technologies. A heightened sense of confidence about the efficacy of antiretroviral treatment in fostering undetectability, and overestimating the potential of a therapy beyond its present value, often reflects an attempt by the participants to render their HIV bodies intelligible in such a way as to present it as harmless, normal, and non-contagious and combating and escaping the experience of stigmatisation of their HIV bodies.

Generally, it was observed that participants constructed their corporealities of HIV non-infectiousness around two categories: normalised body and partially normalised body. These corporeal constructions are the embodied experience that was central to participants' perceptions of the consequences of the therapeutic shift from HIV infectiousness to non-infectiousness, and the role and limit of antiretroviral therapy in facilitating a non-infectious body. Despite normalising and partially normalising the body, the use of antiretroviral therapy does not eradicate the risk of HIV infectiousness, but can only help to manage it under certain conditions.

6.4 Healthwork and the corporeality of HIV non-infectiousness

The biomedicalisation of HIV vis-à-vis HIV non-infectiousness has a great deal of potential in reducing HIV re-infection and transmission rates. Like Squire (2010), Persson's (2013) contention about the trajectory from an infectious body to non-infectious body hinges on adherence to HIV treatment, which represents the major drawback of the overall argument about HIV non-infectious corporeality. Adherence to antiretroviral treatment could be central to the corporeality of non-infectiousness, but what HIV-infected individuals undertake to achieve non-infectiousness corporeality cannot be reduced solely to adherence. This is because the construction of a non-infectious body is now woven around the reduction in the viral load and increase in the CD_4 count in which testing, counselling, and adherence to the HAART regimen are pivotal. In this sense, there are other activities and practices that HIV-positive people undertake in achieving non-infectious corporeality other than just adherence. In other words, adherence is part of the healthwork that participants undertake to achieving the corporeality of HIV non-infectiousness. However, what seems lacking is the question: what role does healthwork play in shaping the corporeal sense of HIV non-infectiousness in everyday life? From the narratives of the participants, four themes emerged about the role that healthwork plays in shaping their corporealities of HIV non-infectiousness, which is the reflection of HIV body-in-themself. These themes, which are reassessment, negotiation, minimisation, and demythologisation, will now be examined in the sections that follow.

6.4.1 Reassessment

Testing shapes the corporeal shift of the participants from an infectious body to a non-infectious body, and thus enables them to compare their previous viral load test results with the latest test result, with a view to reassessing the state of their health and treatment progression. Reassessment is an embodied feeling that involves comparing and reflecting on one's state of health in relation to the latest test results. Reassessment allows the construction of corporeality around HIV body-in-themself—a corporeality that is subject to the gaze of social structure (occupational structure of healthcare profession). With HIV body-in-themself, the expression of a corporeal image is mediated by biological facts (viral load test results), which shape participants' experiences of corporeality and internalised imaginaries in which their bodies and health are evaluated.

Reassessment helps to understand a shift in corporeality, as comparing past and current viral load test results presents a comforting or discomforting image about the body, prompting the HIV-positive individuals to strategically reassess the discrepancies in terms of bodily appearance, meaning of the test result and the bodily feeling about the treatment progression. The sense of corporeality of HIV non-infectiousness stems from how HIV-positive individuals reassess their conditions from previous test results to know whether they are making progress or not. The narratives of Lara, one of the 22 participants in this category, demonstrated how healthwork aided reassessment in a corporeal construction of HIV non-infectiousness:

> I was dying when I came to the hospital. My CD_4 was very low to the level of 8, while my viral load was more than 12,000. The testing I did last week (CD_4 count and viral load tests) shows that the virus is responding well to treatment, and this gave me confidence that everything is well and OK. Now my CD_4 count has increased from 8 to more than 850, while the viral load is below 200. I can now see that my immunity is high, and my viral load has decreased. In the treatment centre, the health staff are always targeting 200 in cases of clients' viral load. The moment it gets to 200, they will say… 'Yes, the drugs are working'. If the viral load test shows anything below 200, they will say there is a possibility of having undetectability. I know I have not arrived at the level of undetectability now, but I know that one day I will get to this level, where I will be part of those who are non-infectious.

The re-enactment of HIV body-in-themself vis-à-vis reassessment is about the participant questioning the result of their viral load test, especially when the latest result shows little or no difference from their previous test result, and then examining whether counselling or medical advice has been followed or the possible cause of poor health improvement. Healthwork enables the re-enactment of HIV body-in-themself vis-à-vis reassessment to take place, as the participant's quest of attaining undetectability, which was the primary goal of the participant; thus, it requires comparison of previous and current viral load test results. This enables Lara to reassess the viral progression through available treatment options and how to overcome the gulf between her current test result and the threshold of undetectability. This inevitably shapes the participant's understanding about the current level of her HIV body. The expressive character of the body towards undetectability under a reassessment regime cannot simply be reduced to a matter of biological facts (viral load test results), but a corporeal character that emerges following the changing patterns of biological facts.

The participant's narrative, that treatment was working but has not yet achieved non-infectiousness, revealed the deepest disposition of corporeality, in which the expectations of undetectability are increasingly conditioned by the measurement of the biological facts. In this regard, healthwork enables the re-enactment of HIV body-in-themself, in which corporeality is expressed following exposure to the gaze of structural inscription.

Unlike Lara, whose reassessment was based on first-line therapy, the narrative of reassessment for Kenny was based on second-line therapy. Kenny (a 48-year-old-woman, living with HIV for 12 years) constructed the corporeality of HIV non-infectiousness, based on the reassessment that healthwork offers in HIV management:

> The moment I woke up in the morning, I take Truvada, then I was on first-line therapy. But now, I'm on second-line therapy because I had surgery for appendicitis in 2011 and a few months after the surgery, I was not able to take my medications. I was later placed on second-line therapy in 2012. That was why I was given Atazanavir as part of the drugs that I'm currently taking. Before the surgery, my CD_4 count was higher, and my viral load was undetectable. What really led to the change of therapy after surgery was that my viral load has increased from less than 20 to more than 25,000 and my CD_4 count has dropped from 750 to 350. Truvada and Nevirapine are parts of the drugs regimen that I took in my first-line therapy prior to my surgical operation, but when it was not effective after surgery, that made them to change me to second-line therapy. The doctor told me that my immunity was weak when compared to when I was on first-line therapy, and that I cannot return to first-line therapy but rather switch to second-line therapy. Each time I reflect on this, I'm not happy. This is because, despite all efforts, I have not been able to return to undetectability since the surgery.

The corporeal orientations of the participant towards undetectability stemmed from the reassessment of the previous and current test results on viral load and CD_4 count. With reassessment, the participant experienced her body as expressive and responsive to biological facts that carry an aura of immediate salience, which structured her imaginaries of the body within certain patterns of intra-corporeal encounters. Through testing, the participant's corporeality of non-infectiousness was forged based on reassessment of the viral load test. The comparison of the test outcomes in pre-and post-surgery demonstrates the centrality of healthwork in understanding how undetectability becomes the basis through which HIV-positive individuals reassess their viral conditions, with a bid to constructing non-infectiousness corporeality on that basis. The construction of the participant's corporeality of HIV body-in-themself demonstrates that the HIV body has now been exposed to the inscription of the social structure in which occupational gaze of healthcare professionals hold sway.

Healthwork therefore enables the participants to undertake an intra-corporeal evaluation of whether their bodies are still infectious, becoming non-infectious or have attained non-infectiousness through reassessment, and this hinges on the treatment effects on the viral load, and possibly CD_4 count that testing made available. The comparative assessment of previous and current tests underlies the infusion of healthwork as a form of reflexivity, grounded in the corporeal realm of HIV non-infectiousness. The participant’s reassessment of her body in response to the effects of treatment on HIV undetectability, following medical encounters with healthcare professionals, is part of the corporeal expression of HIV body-in-themself, in which healthwork helps to facilitate HIV management.

6.4.2 Negotiation

Being infected with HIV stripped HIV-positive individuals of their agencies in exercising discretion over what they can do with their bodies, with respect to the continual usage of antiretroviral drugs, having unprotected sex, blood transfusion and organs donations. The HIV body, therefore, inhibits the ability of HIV-positive individuals to negotiate around these domains. Healthwork thus helps the participants to negotiate the sense of their HIV embodiment within the windows of opportunity offered by undetectability. Like reassessment, the awareness of the negotiated corporeality is an expressive feature of an awareness and comparison inherent in biological facts, which is the construction of HIV body-in-themself for the participants. With negotiation, the participants are performing expressive body within their subjectivities, in which the HIV body is being re-imagined as a negotiated entity.

Healthwork helps to re-imagine the HIV bodies as ‘eligible’ and ‘ineligible’ for negotiation based on the effects of treatment action on the level of detectability and undetectability. If the result of the viral load is detectable and labelled ineligible, there is no basis for participants to start negotiation. In this sense, healthwork therefore enables the re-enactment of HIV body-in-themself through negotiations, as the negotiated body is expressed as having a certain form which positions the mind in intra-corporeal space. Ten participants saw undetectability as an opportunity to start embodied negotiation, using the result of the viral load to explore ways of circumventing the limit imposed by HIV infectiousness as the corporeal demonstration of HIV body-in-itself. Undetectability is a recipe for the eligibility for negotiation, as healthwork thus allows the participant to know the eligibility for negotiation, and to delay negotiation when such eligibility has not been met.

The narrative of Ade (a 48-year-old man, who has been living with HIV for seven years) added important weight to this position:

> The day that I got the result that I was undetectable, I was extremely happy that I won’t be infecting my wife without using a condom. To be honest, it has been long since I had unprotected sex with my wife, who is HIV negative. By having drugs that can make one to be undetectable shows that very soon the cure for the virus will be found.

The re-enactment of HIV body-in-themself is ensued when the participant activated his embodied negotiation by exploring the avenue to engage in unprotect sexual practice following the undetectability of a viral load result. By starting negotiation, the participant has appraised his eligibility for negotiation with his body and constructed corporeality that allows him to problematise the lack of unprotected sex as denormalisation that HIV non-infectiousness/undetectability seeks to address and change. Healthwork thus allows the participant to know the eligibility for negotiation, and to activate it when eligibility has been met. The narrative of Kay (a 44-year-old-man, who has been living with HIV for four years) has further demonstrated how healthwork has fostered negotiation in the corporeal construction of HIV non-infectiousness:

> When my viral load test shows undetectability, then I said to myself that I can now have occasional unprotected sex with my un-infected partner, but I don’t think I will be able to donate blood for others in need of it. This is because I still believe that the virus in still in my blood. It is undetectable because I have been taking medications for a long time now, and such medications supress it from being detected.

Although HIV undetectability allows the participant to start negotiation, it does not put him in a strong position during negotiation due to the risk of blood transfusion and fear of viral presence (despite undetectability) that are imposed by HIV infectivity. HIV undetectability only brings the participant to the table or level of awareness where the aspect of embodied limitations imposed by HIV infectivity can still be negotiated and circumvented with their bodies. Healthwork vis-à-vis testing (viral load), therefore, facilitates negotiation by revealing the eligibility for engagement in blood donation and sexual practice and helps in the re-enactment of HIV body-in-themself with respect to whether it is possible to engage in sexual practice, and when to engage in sexual practice. Therefore, negotiation based on the corporeality of undetectability is part of the embodied construction of HIV non-infectiousness that healthwork helps to foster in HIV management.

6.4.3 Minimisation

One of the consequences of HIV-related stigmatisation, as demonstrated in the previous section, is the enactment of HIV body-in-themself that emanated from the sense and feeling of being ‘othered’ from the rest of the society. Healthwork has helped to minimise a sense of otherness fostered by felt and enacted stigma and to reduce the negative cultural attitudes against the participants. The therapeutic breakthrough inherent in HIV treatment, and anchored by the healthwork, helped to minimise the spate of otherness, stigmatisation, and HIV-related discrimination experienced by the participants in public spaces.

The corporeal construction of minimisation is an expressivity and re-imagining of HIV bodies as part of the inter-corporeal practices that relates more broadly to the shared social world. Minimisation is the demonstration of HIV body-in-themself, in which healthwork played a crucial role in social life. The narrative of Sida (a 36-year-old-woman, who has been living with HIV for nine years) attests to this reality:

> I used to be invited to a TV programme on HIV, and each time I attended the programme, the staff of the TV station (apart from the presenters) openly discriminated against me by segregating their stuffs and themselves from me. During the TV programme, I talked about the latest development around HIV undetectability, using my undetectable case as an example. I said on the programme that I have been having unprotected sex with my husband for some time, and yet my husband is still HIV-negative. Immediately after the programme, the same staff asked me to clarify what I said about undetectability and I asked them to Google it, which they did. As a regular guest who has been on the TV programme six times since then, the staff changed their attitude to me, we became friends and they sometimes used to call me on the phone to say ‘Hello’. If I had not been taking my drugs daily, I don’t think I could get to an undetectability stage, and I wouldn’t be talking about my experience to others on TV.

The performance of HIV body-in-themself as far as minimisation is concerned is the expression of the HIV body in terms of an imaginary reality, located within the inter-subjective practices. Through healthwork, the feeling of otherness that emanated from felt and enacted stigma has minimised and reduced, as can be attested in the participants’ accounts. This was made possible following the evidence of undetectability by the participants or their partners. The therapeutic shift towards undetectability does not inevitably lead to minimisation unless evidence of undetectability and non-infectiousness is communicated to others and understood by them. This can be seen in Sida's narrative above. With minimisation, the re-enactment of HIV body-in-themself is the understanding of the meaning and symbolic structure that shape the connection between the participants and the cultural inscription. The participant's corporeal sense of otherness, which emanated from enacted stigma, has been reduced following people's awareness of her own undetectability. Minimisation does not indicate that larger cultural changes towards de-stigmatisation have ensued, but such changes are underway as more and more people are made aware of HIV undetectability. Healthwork helped to foster minimisation vis-à-vis adherence and testing, but without the campaigns and media coverage, there would not be a shift in attitudes that could have led to a minimisation of HIV-related stigmatisation and discrimination in social life.

Unlike Sida's experience that was based in an urban centre where the TV station was situated, Davis' experience of minimisation was based in a rural area. The narrative of Davis (a 58-year-old-man, living with HIV for 11 years) demonstrated how healthwork helped to facilitate minimisation in the corporeal experience of HIV-related discrimination and stigmatisation:

> During HIV awareness week, I joined other members of the support group to embark on an awareness campaign in a small town, so that people in a rural area can know more about HIV and change their attitudes to testing and people living with the virus. When we got to the market, I used my experience of HIV undetectability to inform people who came to the market that HIV is not infectious like before. The leader of the market's women's association came out and told us to leave the market because HIV is dangerous and contagious. Fortunately, one of the traders' children, who happened to be a university student, came from nowhere and told the woman leader to leave us alone, saying HIV is no longer infectious if its undetectable and if HIV-positive individuals continue to take their medications daily. Those traders believed her and said 'they did not know that HIV has changed from what they knew about it previously'. They welcomed us, interacted with us and they gave us free stuffs like food, detergents, and the transport fare. If we look unwell and unhealthy, they will not believe our story on undetectability, not to talk giving us an audience and changing their attitudes towards us.

Healthwork enables the door of opportunity that mediates the perpetual encounter of the participants as part of the intersections with others. The narrative of the participant revealed that HIV-related discrimination and stigmatisation, rooted in the cultural understanding of HIV, still exists, especially in the rural areas of Nigeria.

The corporeal process that ushered in minimisation is the enactment of HIV body-in-themself, where the embodied feeling of a gradual de-othering emanated from the awareness of HIV undetectability and non-infectiousness. HIV undetectability is legitimised by testing, which adherence has helped to attain. The instrumentality of adherence and testing, as components of healthwork, helped to achieve undetectability that led to a reduction in a negative cultural bias against the participant and fostered a gradual de-othering in enacted stigma. Deepening this gradual de-othering within the larger cultural space requires the importance of visibility and the publicisation of treatment outcomes (undetectability) in shaping the local cultural understanding of HIV through awareness campaigns. The corporeality of minimisation experienced by Davis was the expression of HIV body-in-themself in everyday life. Nevertheless, there exists a gulf between minuscule de-othering that participants experienced and the substantial scale of otherness and culturally inscribed stigmatisation that occurs in Nigerian society to this day.

6.4.4 Demythologisation

The corporeality of dirty body that participants constructed in the previous section was rooted in religious-based stigma and discrimination against HIV and those living with the condition, which continues to exist even up to today. The therapeutic shift towards HIV non-infectiousness and undetectability does not render the hold of religious beliefs on everyday life of the participants invalid, but rather provided the basis for deconstructing the religious myth on which the corporeality of dirty body was constructed. Demythologisation is about deconstructing the myth of religious belief around the construction of dirty body, by considering the body as an infectious entity that can attain undetectability and non-infectiousness. The shift from dirty body to infectious body is the construction of the corporeality of HIV body-in-themself, which healthwork helps to facilitate.

The corporeal nature of demythologisation is an expressive feature of a reflexivity rooted in biological facts against the gaze of the religious inscription of HIV. With demythologisation, the corporeal sense—that the body is an infectious container that does not conform to the myth of dirty body if undetectability is to be attained—is constructed. Healthwork helped the participants to deepen demythologisation, by informing the participants about what undetectability actually means and working towards achieving undetectability and non-infectiousness in their daily lives.

The narrative of Funmi (a 34-year-old-woman, living with HIV for three years) has demonstrated how healthwork has helped to intensify demythologisation in the daily and social lives of people living with HIV:

> For the fact that I got HIV does not mean God does not love me or that I am a sinner, may be that was the reason why I got HIV. I got HIV through sexual contact. Now there are medications that can make HIV undetectable, and I am working towards achieving that. I don't believe any longer that I have a dirty body because I have HIV.

The knowledge that non-infectiousness is a possibility helped to weaken the hold of religious beliefs about dirty body in the lives of the participants, as the practical reality of undetectability became the scientific fact that shattered the corporeal myth of dirty body—that was powered by the religious narrative. In demythologisation, the expressivity of the corporeal dimension of HIV body-in-themself is rooted in the participant's embodied awareness and reflexivity of undetectability as a counterweight to enacted stigmatisation of dirty body. Healthwork (especially through support group participation and internet use) enabled the participant to navigate away from the corporeal domination of dirty body and towards the attainment of infectious corporeality. Therefore, healthwork helps not only to enable the demythologisation to occur, as the narrative of Funmi above suggested, but also helps to deepen the wave of demythologisation in an HIV context. In this regard, adherence, counselling, testing, support group participation and internet use are the important drivers of demythologisation, and the basis through which a therapeutic shift towards non-infectiousness is made possible.

Unlike Funmi, whose account of demythologisation was based on personal experience, the narrative of Bimbo (a 38-year-old woman, who has been living with HIV for 10 years) demonstrated how healthwork helped to achieve demythologisation based on her roles as an HIV counsellor and as one of the support group's executives:

> One of the members in our support group told me that he left a church because the presiding pastor condemned HIV and said it was a dirty disease associated with dirty people. I supported him to leave the church and go elsewhere, because HIV is a disease that can be managed and can also be

> non-infectious if you take your medications daily. We don’t have a dirty body. We are only living with HIV.

With demythologisation, the participants are performing expressive body within their subjectivities, by navigating away from the corporeality of dirty body, and thus the re-imagined HIV body as an infectious entity. Bimbo’s narratives mapped out how healthwork helped to foster demythologisation in participants’ lives, by enabling participants to consider their bodies as infectious entities that can be non-infectious if undetectability is attained. Adherence became the major driver of demythologisation in practice, because it provided the pathway for participants to consider undetectability and non-infectiousness as the basis of demythologisation in their daily lives. Finally, the participants’ quest towards achieving undetectability enabled demythologisation to occur, as they construct non-infectious corporealities as a possible deconstruction of the myth of the dirty body. Demythologisation does not connote those participants who abandoned spirituality, but only demonstrated the limit of spirituality in achieving non-infectiousness and undetectability.

Generally, the notions of reassessment, negotiation, minimisation, and demythologisation that are observed as the impact of healthwork on the corporeal construction of HIV non-infectiousness has thus reaffirmed the previous argument in this chapter, that achieving non-infectiousness cannot be reduced solely to adherence. Healthwork helps to foster the re-enactment of HIV body-in-themself through the corporeal sense of reassessment, negotiation minimisation and demythologisation, having expressed a certain form of expressivity that coalesces around intra-corporeal and inter-corporeal subjectivity. By balancing the expectations of undetectability against the cultural gaze and structural reality of enacted stigma/stigmatisation, healthwork helps to shape the corporeality of HIV body-in-themself towards experiencing or imagining non-infectiousness, as reality that can be achieved.

The construction of corporeality of HIV non-infectiousness, through the framework of HIV body-in-themself in this chapter, revealed that adherence plays a central role, but in combination with other elements of healthwork such as testing, counselling, concealment, and spirituality. Therefore, the unmasking of reassessment, negotiation, minimisation, and demythologisation as the impact of healthwork offers insight into taken-for-granted aspects of HIV management, that are not only woven into the biography of people living with HIV, but rather become part and parcel of their daily lives.

6.5 Conclusion

This chapter has explored the constitution of the body and healthwork in everyday management of HIV within the framework of corporeality. This corporeality, which is in the form of HIV body-in-themself, has demonstrated its dimensions in the participants' narratives as otherness, dirty body, and infectious body in the Nigerian context. These corporeal expressions—otherness, dirty body, and infectious body around their HIV infectiousness—were drawn from existing cultural schema, religious inscription, and a biomedical frame of disease causation. These findings help to address the first question of how HIV-positive individuals construct the dimension(s) of the corporeality of HIV body-in-themself, that was posed at the beginning of this chapter.

This chapter further delved into the analysis of how HIV-positive people construct their corporealities of non-infectiousness following the recent debate about the potency of antiretroviral therapy in ushering non-infectiousness, as stated in the Swiss Consensus Statement, and the impacts of healthwork on shaping and reshaping corporeal realities of infectious/non-infectiousness in HIV management.

However, following the nascent trajectory of HIV body from infectious to non-infectious corporeality that was inspired by the Swiss Consensus Statement and recent global HIV policy tagged 'Treatment-as-prevention', the participants' understanding of non-infectiousness is revealed in their corporeal constructions that coalescence around two categories: normalised body and partially normalised body. The findings on normalised body corroborated the works of Squire (2010), Persson (2013) and Mazanderani and Paparini (2015) that antiretroviral therapy has indeed fostered normalisation, or normalised body, that can prevent HIV non-infectiousness through unprotected sex. However, the findings about participants who constructed partially normalised body contrast with the position of Squire (2010), Persson (2013) and Mazanderani and Paparini (2015).

The participants argued that antiretroviral therapy did not foster a normalised body (normalisation) or has full impact on HIV non-infectiousness. It was observed that antiretroviral therapy can only guarantee limited sexual intercourse (in the case of

PMTCT) and a limited period of breastfeeding, but cannot prevent infectiousness through blood transfusion and organ donations/transplant despite HIV undetectability. This finding shares empirical support with Young et al.'s (2016) observation, that there is a disjuncture between lay and expert understanding in the biomedicalisation of HIV non-infectiousness. The lay perspective of those who constructed partial normalisation does not align with expert understanding of full normalisation, as they did not feel their body had been normalised to guarantee non-infectiousness. However, what was observed from the participants' corporeal constructions of non-infectiousness around normalisation and partial normalisation is the expectation that undetectability relates to cure. With undetectability as related to cure, participants maintain unrealistic expectations of cure as the important intervention that effective antiretroviral therapy can do for them. It can be theorised that people living with HIV aspired to attain HIV undetectability because of two reasons. The first is the belief that undetectability is the pathway to a future cure of HIV, as attaining undetectability means getting closer to the cure. The second is that undetectability provided the participants with mental fortitude to escape the infectious and stigmatised characters of HIV that featured intensely in cultural and social imaginations. This construction of high expectations is necessary for the management of HIV, as the participants present their HIV bodies as harmless, normal, and non-contagious and, thus, enable them to combat the spate of stigmatisation around their conditions. The expectations of the participants in relating undetectability to the cure is buoyed by hope, in that advancement in HIV therapy means that science is getting closer to developing an HIV cure. The participants' expectations revealed the over-estimation of undetectability as related to prevailing curative reality. This further demonstrates the contrasting evaluations between professionals (clinicians/scientists) and lay people (the participants) about the current potentiality of antiretroviral therapy in fostering a cure.

The findings on participants' construction of HIV non-infectiousness have helped in addressing the second question, of how HIV-positive people construct their corporealities of non-infectiousness, that was posed at the beginning of this chapter. However, participants' construction of HIV non-infectiousness cannot be achieved without the imprimatur of healthwork, as adherence, testing and support group participation are observed to be central in shaping the corporeality of HIV non-infectiousness.

Subsequently, the findings in this chapter help to illuminate the therapeutic shift from infectiousness to non-infectiousness that healthwork fostered among people living with HIV. However, this therapeutic shift has not resulted in a cultural shift in terms of changes in the cultural understanding of HIV within the larger Nigerian society. The therapeutic shift only led to a cultural shift among people living with HIV through a minimisation of negative cultural attitudes and stigmatisation and otherness attributed to HIV positivity, as well as demythologisation that weakens the hold of religious beliefs about the dirty body in the lives of people living with HIV, as the practical reality of undetectability shattered the corporeal myth of the dirty body that was powered by the religious narrative. To ensure that this therapeutic shift leads to a cultural shift within the larger Nigerian society, the importance of visibility and the publicisation of non-infectiousness, undetectability and treatment outcomes in shaping the local cultural understanding of HIV are required. Without publicisation of treatment outcomes and the latest therapeutic advances in antiretroviral therapy that reduce the level of the virus in the body to an undetectable level and render HIV sexually untransmittable (Keogh 2017), there will not be any attitudinal and behavioural changes about HIV and, in turn, towards people living with HIV.

Finally, the corporeal construction of reassessment, negotiation, minimisation, and demythologisation, as the impacts of healthwork on the corporeality of HIV non-infectiousness, is rooted in the re-imagining of HIV body-in-themself as part of the inter-corporeal practices that relate more broadly to the shared social world, and everyday lives, of the participants. Since it has been observed that treatment, or adherence to treatment, is insufficient to facilitate HIV non-infectious corporeality, the participation in healthwork in terms of counselling and testing is equally important as adherence in ushering HIV non-infectiousness and, thus, deconstructed the therapeutic reductionism implicit in biomedicalisation of the HIV-prevention discourse (Persson 2004; 2013; Squire 2010; Mykhalovskiy 2010; Nguyen et al. 2011; Kippax & Stephenson 2012; Young & McDaid 2014; Young et al. 2016). Without healthwork, the impact of these great gains, in the context of the effective management of HIV in everyday life in this corporeal era of HIV undetectability and non-infectiousness, would be greatly diminished in personal, practical, and policy contexts.

As part of the BBC chain, the previous chapter has explored biographical time and healthwork in an HIV context. This chapter has addressed the constitution of the body and healthwork in the everyday management of HIV within the framework of corporeality. The next chapter will examine the last component of the BBC chain, which is self/identity. Therefore, understanding how self and identity are constituted or central to the participation in healthwork will be explored in Chapter Seven.

CHAPTER SEVEN

THE CONCEPTION OF SELF AND HEALTHWORK IN HIV MANAGEMENT

7.1 Introduction

The previous chapter explored how HIV-positive people constructed their infectious/non-infectious corporealities and the impacts of healthwork on shaping and reshaping this disrupted sense of corporeality. Building on this, this chapter seeks to explore how HIV-positive people construct their sense of self following HIV diagnosis and the impact of healthwork on HIV-positive individuals' sense of self in everyday life. Self is defined here as *how we see ourselves*. Self, therefore, is the personhood that individuals internalised as part of their personality (Baumgartner 2007).

Yet, self cannot be divorced from identity, as identity is created when self is developed (Baumgartner 2007). When considering background research on self within an HIV context, discussion of identity seems inevitable (Sandstrom 1990). This is because the new identity ensues when HIV is legitimised, and this new identity shapes or becomes part of the new self that emerges following HIV diagnosis. Identity here is defined as *how participants constructed who they are in relation to how they are perceived by others following their new health circumstances*. From the perspective of HIV-positive individuals, identity is who they are in relation to how others define their condition or define them based on their diagnosis of HIV. Therefore, understanding how the new sense of self is shaped by having a positive-HIV status will be explored in this chapter. The exploration of this issue requires inquiry into how people living with HIV have constructed their sense of HIV identity, which will be undertaken first in this chapter, as this will provide a pathway towards understanding how the constructed sense of HIV identity is installed into their sense of self in an HIV context.

HIV does not only alter and disrupt the biographical temporality and corporealities of people living with HIV, as demonstrated in Chapters Five and Six respectively; rather, it also changes their sense of self. When HIV ensues, the pre-diagnostic self (self that was possessed prior to illness) is disrupted and changed in the light of new circumstances of HIV; these changes result in the development of the post-diagnostic self (self that ensues after diagnosis). How people living with HIV see themselves changes due to the meaning and stigma around HIV (Rohleder & Gibson 2006). The self of HIV-positive individuals is altered following the onset of HIV, and such an alteration does not lead to a loss of self but changes in self. Those changes in self consist of changes from the pre-diagnostic self to a post-diagnostic self. With change in self, HIV-positive individuals construct a new sense of self that takes or accommodates most of the attributes of the pre-diagnostic self that are retained, and adds changes that the disruption of the illness brought into it, to make a post-diagnostic self. Being diagnosed with HIV generates identity (Flowers et al. 2006), and that identity stems from the stigma around HIV, which can be regarded as a 'spoiled identity' (Goffman 1963). The post-diagnostic self is forged due to the stigma around HIV identity. Stigma in this case is synonymous with identity that the participants internalise as part of their post-diagnostic self.

The exploration of this new understanding of self and identity is undertaken in this chapter to unpack the primacy of healthwork in sustaining the post-diagnostic self and maintaining a new identity as far as everyday management of HIV is concerned. Understanding what constitutes the post-diagnostic self in the context of HIV is particularly salient towards exploring the impact of healthwork on the post-diagnostic self.

Having established that the pre-diagnostic self and the post-diagnostic self are different as far as the context of illness is concerned, and that the latter is more useful in the exploration of how self is constructed in the HIV domain, reframing the initial questions around the post-diagnostic self seems more plausible. In this regard, the questions to be addressed in this chapter are the following: How is the post-diagnostic self constructed by HIV-positive individuals following the onset of HIV? How does HIV identity shape the sense of the post-diagnostic self? What are the impacts of healthwork on the post-diagnostic self?

Since the post-diagnostic self cannot occur without the new identity that ensues following HIV diagnosis, section 7.2 seeks to explore how HIV identity shapes the sense of the post-diagnostic self. Thereafter, section 7.3 will be devoted to understanding what the post-diagnostic self constitutes, with a view to exploring how it was constructed by HIV-positive individuals following HIV diagnosis. The impacts of healthwork on the post-diagnostic self will be explored in section 7.4. The discussion and conclusion will be undertaken in section 7.5.

7.2 The nexus between identity and self in an HIV context

In an illness context, the sense of the post-diagnostic self cannot be fully formed and constructed without being shaped by the illness identity that ensued in the aftermath of a diagnosis. The nexus between the post-diagnostic self and HIV identity stems from how they are shaped and reshaped in never-ending dynamics. The result of an HIV-positive test does not only affirm the presence of the virus in the body, but also has the ‘capacity to generate identities’ (Flowers et al. 2006: 120), and part of that category of identities is the HIV identity. The social shaping of the post-diagnostic self by HIV identity ensues when the individuals internalise who they are in relation to how they are defined by others and their reactions to how others define their HIV conditions. How is the conception of the post-diagnostic self shaped by HIV identity? This is an important question that this section seeks to explore. Addressing this question will require exploration of how the participants constructed their identities around having HIV and how these identity constructions shape the conception of the new self in the HIV context. Following the narratives of the participants, two forms of identities emerged around HIV positivity: stigmatised identity and unhealthy identity.

7.2.1 Stigmatised identity

The social stigma around HIV shaped how people living with HIV understand who they are (identity) in relation to the stigma attached to HIV by others in society. Even though the participants describe the impact of antiretroviral treatment on their body as effective, the common theme among 10 of the participants about how identities were constructed revolved around a stigmatised identity due to how others define their HIV positive condition. Funmi (a 34-year-old-woman, who has been living with HIV for three years) narrated how her HIV identity is constructed around a stigmatised identity:

> To be sincere, HIV is a painful thing to me… I’m managing my condition. In fact, I don’t know how to say it. I am ok, but the moment I thought of HIV, I feel dejected. I’m ashamed to say I have HIV publicly because people will say I’m promiscuous and adulterous, that is what HIV is associated with. I am now part of those people regarded as contagious and dangerous. Having HIV does

> not give me the voice to publicly disclose my condition. It does not allow me to openly disclose the type of drugs that I'm taking and its efficacies. It seems as if I'm in another world. My present life is painful to say the least.

How people living with HIV see themselves changed due to the meaning and stigma around HIV identity that exists in Nigeria. What produces a stigmatised identity from the participants' narrative is the cultural understanding of HIV, which culminated in the way in which society looks at and relates with HIV-positive individuals. This cultural understanding of HIV in Nigeria produces what Scambler and Hopkins (1986) described as felt stigma (expectation and shame of discrimination that prevents people from talking about their experiences and prevents them from seeking help) to the participant. According to a cultural inscription of HIV in Nigeria, HIV infection is self-inflicted and synonymous with those who are promiscuous and adulterous (Tocco 2010), and the participant's construction of this cultural inscription demonstrated how HIV could generate a stigmatised identity for people living with HIV. For Funmi, having HIV could have a devastating impact on their identity because of its consequences that serve as a moral shame to those who had the ill luck to be infected by it. The participant's inability to undergo HIV public disclosure has demonstrated not only how stigmatised identity has shaped her post-diagnostic self, but further demonstrated the nexus between a stigmatised identity and the social context in which HIV is lived and produced.

Unlike Funmi, whose sense of felt stigma shaped the construction of stigmatised identity, the enacted stigma (that is, the experience of unfair treatment by others) experienced by another participant, Omooba (a 57-year-old-man, living with HIV for 30 years), shaped how the sense of a stigmatised identity was forged in his understanding of HIV:

> When I was diagnosed with HIV, I felt ashamed that I have this dirty disease. But the more I concealed it, the more it becomes a burden to me. To free myself of that bondage, I came out and I announced my HIV status publicly. In fact, when I disclosed my HIV status on radio, television, and mass media, a lot of people got to know my status and they avoided me in public spaces like church, the market, etc. Even those who I used to interact with them before, I observed that they suddenly ran away from me. Not that I have regret for disclosing my status but seeing myself as part of those people who are running away from me, is just too depressing and shameful.

The participant’s construction of an HIV identity around a stigmatised identity hinges on the social representation of HIV in the society and the enacted stigma he experienced. Omooba tried to challenge the felt stigma associated with HIV by speaking publicly, but negative public reaction to such a public disclosure further reinforced the stigmatised identity that later became part of his post-diagnostic self. The participant’s personal construction of HIV as a stigmatised identity is reflected in his lived experience of ‘enacted stigma’ (Scambler & Hopkins 1986), that was derived from communicative interactions within a particular social context. The consequence of HIV disclosure is seen in the way in which a stigmatised identity shapes the way the participant makes sense of his new self around social reactions to being diagnosed with HIV. Therefore, the stigmatised identity that HIV-positive individuals constructed around their condition is constitutive of active interactions between them and others within the social environment in which HIV is experienced.

7.2.2 Unhealthy identity

The second identity is unhealthy identity. HIV diagnosis challenges the identities of HIV-positive individuals as healthy people (Wekesa & Coast 2013). The consequences of HIV diagnosis have implications on HIV-positive individuals in relation to how they see themselves and as they are perceived by others (Freeman 2016). These consequences consist of an alteration in the way HIV-positive individuals attach meaning to social situations around them. One of the widespread negative social constructions of HIV in Nigeria is that HIV-positive individuals are unhealthy because they live with a disease that has no cure (Tocco 2010), and the theme of unhealthy identity that ensued from HIV-positive status has been found in the narratives of 22 participants. The narrative of Davis (a 58-year-old-man, living with HIV for 11 years) demonstrated this position more succinctly when he stated the following:

> When I was told that I have HIV, I was not happy. I was tired of everything, including life. Even though I was not sick at the time, I still feel unwell and unhealthy till now.

The participant’s construction of an unhealthy identity around his condition is a reaction to how HIV-positive individuals understand who they are, following the HIV diagnosis. One of the reasons why HIV is stigmatised is because it is seen as contagious (Tocco 2010). This contagious nature of HIV constitutes a basis for the construction of an unhealthy identity by the participant. The nexus between a stigmatised and an unhealthy identity is reflected in how a contagious disease like HIV becomes a health problem for the participant due to the presence of the virus in his body. This rhetoric around the unhealthy nature of HIV stems from the cultural explanation that affirmed the presence of the disease/virus as the symptoms of ill-health to the participant. The construction of an unhealthy identity is a way of reaffirming the cultural understanding of HIV and inculcated into the post-diagnostic self. Therefore, an unhealthy identity represents a set of meanings that the participant attributes to himself, while taking the perspectives of others in the society.

The narrative of another participant, Betty (a 45-year-old woman, living with HIV for 11 years) demonstrated how an HIV identity was constructed around an unhealthy identity:

> I was sad and ashamed of myself when I knew about my HIV status. Then I said to the doctor ‘Is it not the HIV that people said it kills?’ The doctor in charge said to me that ‘HIV is not a problem as long as I take my medications as prescribed’. Why am I taking drugs every day if I am healthy? I don’t think I was healthy, even now.

The unhealthy identity of the participant was constructed around a cultural understanding of HIV and her understanding on medication use. The initial construction of an unhealthy identity by the participant was a reaction to how HIV-positive individuals are perceived in Nigerian society and how she was taking the perspectives of others in the society. In other words, the participant’s construction of an unhealthy identity around her condition was underscored by the cultural inscription of HIV, and how that pattern of such an inscription shapes her responses that culminated into the construction of an HIV identity. This implies that an unhealthy identity was socially produced and became part of the attributes of her post-diagnostic self.

Subsequently, the participant’s questioning of why she needed to take medication demonstrates how the meaning of medications shaped the construction of an unhealthy identity. From the narratives, the act of taking medication daily means being ill and unwell, even where an interactional context tends to debunk having HIV as an unhealthy issue. The implication of this was that, even if the participant later became non-infectious, such non-infectiousness would not be enough to deconstruct the unhealthy identity. Therefore, the participant was constructing a new unhealthy identity based on the cultural representations of HIV and daily medication use as symbols of unhealthiness and daily use of medications.

The participants' construction of both stigmatised and unhealthy identities around their HIV identity was part of the construction of their new identities and as part of the ways of managing HIV in everyday life. These findings share theoretical support from a symbolic interactionist framework and affirm that HIV-positive individuals are continually or constantly interpreting and making sense of the symbolic meaning of HIV in their environment, and thus constructed HIV identity as stigmatised and unhealthy identities in relation to that premise. The construction of the HIV identity around stigmatised and unhealthy identities formed the basis for the construction of the post-diagnostic self of the participants, which will now be explored in the section that follows.

7.3 HIV diagnosis and the transition to a post-diagnostic self

Kathy Charmaz asserted that chronically ill patients lose their selves without simultaneous development of equally valued new ones (Charmaz 1983). Therefore, Charmaz argued that the loss of the aspects of self resulted in a less-valued self. Charmaz's work is fundamentally salient towards unpacking the role that self plays in chronic illness management. However, applying Charmaz's framework to HIV is incomplete. What is limited in Charmaz's conceptualisation is the inability to articulate which aspects of self are lost and which aspects of self are retained following the onset of a chronic illness, especially HIV.

The self in Charmaz's parlance is the pre-diagnostic self that was altered and disrupted by the onset of a chronic illness, and such a disruption resulted in the development of a less-valued self as previously stated. This less-valued self is regarded in this study as the 'post-diagnostic self'. Therefore, the disruption brought about by the onset of a chronic illness to the pre-diagnostic self led to the emergence of the post-diagnostic self. It has been established in Chapter Two that the kind of self that Charmaz and others explored in their studies is the pre-diagnostic self (the impacts of chronic illness on the pre-diagnostic self) rather than the post-diagnostic self. Therefore, the question of how the post-diagnostic self was constructed by HIV-positive individuals is the gap that this chapter seeks to explore and fill with its findings.

Before addressing this question, it is important to argue that the post-diagnostic self cannot sustain a chronic illness in the everyday lives of the patients/ill persons without the will to live with the condition. The will to live with the diagnosed condition is an important facet of the post-diagnostic life. The will to live is the orientation of the post-diagnostic self towards striving for survival and its inculcation into the fabric of the patients' lives. The will to live is the acceptance that the quest for survival is the best course of reaction to the new condition they find themselves living with. The post-diagnostic self exists side by side with the will to live with the condition and shapes each other in a never-ending fashion.

The post-diagnostic self is the perception of who we are in the light of an illness diagnosis, and the will to live with the diagnosed condition enables the post-diagnostic self to further accommodate the illness into their post-diagnostic lives. Furthermore, the transition from the pre-diagnostic self to the post-diagnostic self cannot occur if chronically ill persons do not accept their illness diagnosis or if they are in denial. For instance, the narratives of a participant demonstrated this clearly when stating the following:

> **Joy:** I first got to know my status through HIV screening done in the local catholic church and there was nothing like post-counselling or pre-counselling. After the screening [test], I returned a few days later to collect the result. The test result was heartbreaking and I said God forbid it. I shredded the test result sheet and trashed it in the street bin. I rejected it and I was in a state of denial for about a year and a few months. It was when I was down with opportunistic infections that I went for another test before I started receiving treatment.

The post-diagnostic self cannot emerge if the chronically ill person rejects their diagnosis or is in denial. The rejection of the HIV diagnosis depicts the continuation of the pre-diagnostic self, or that HIV diagnosis does not have any consequence on the pre-diagnostic self. The transition to the post-diagnostic self commences only when the chronically ill individual accepts the changes brought about by the diagnosis. As patients reject their diagnosis, they continued with their pre-diagnostic selves, as the account of the participant above revealed. In the case of Joy, denial depicts a non-acceptance of her HIV diagnosis. Even though some participants expressed denialism initially, they later accepted their condition like Joy following the onset of HIV-opportunistic infections. The moment an HIV diagnosis is disclosed to the participants, it marks an important social phase that alters their sense of who they are. The impact of this diagnostic pronouncement, as Jutel (2015) articulated, demonstrates that diagnosis only has power when it is accepted by the patients. The acceptance of such a diagnosis illustrates the defining moment that changes their understanding of who they are, especially when such a condition is chronic and has negative stereotypical connotations attached to it in the society where the participant lives.

The time lag between the period of denial and acceptance does not have consequences on how the participants live with their conditions, as they eventually accepted that they have HIV and are ready to live with it, even though participants only accepted their diagnoses because of the opportunistic infections. In the context of HIV, the post-diagnostic self of the participants initially ensues when HIV diagnosis stigmatises the infected persons and marks them as unhealthy subjects. For instance, the narrative of Sattu (a 30-year-old woman, living with HIV for five years) demonstrated how the will to live with the condition is crucial to the post-diagnostic life and constituted an important influence on the post-diagnostic self:

> When it comes to the medications, I don’t have any options and I don’t want to die prematurely. If I have options, I will stop taking the drugs… This is the reality of what I found myself in now.

As the chronically ill persons accept that they are ill or have been infected and accept their diagnosis, changes to the pre-diagnostic self ensues and the onset of the post-diagnostic self begins. Then the questions of ‘Why me’, ‘Why now’ may arise, following the emergence of the sense of less-valued selves in the aftermath of HIV diagnosis.

The participant’s will to live with HIV is reflected by the changes made to the self-image that an HIV diagnosis has imposed on it. The construction of the will to live as an important complement to the post-diagnostic self is exemplified by the awareness that daily use of HIV medications has changed the pre-diagnostic sense of self to the post-diagnostic self, in which the quest for survival now remains priority. The important feature of the post-diagnostic self that was observed in this study is the quest to commit suicide. The cultural understanding of HIV shaped the post-diagnostic self of some participants, as they lost their will to live with HIV. The quest to commit suicide, as the immediate reaction of Yemmy (a 47-year-old woman, living with HIV for 12 years) to HIV diagnosis, demonstrates the onset of the post-diagnostic self:

> When I heard that I had been diagnosed with HIV, ah… that day was terrible, but I give glory to God. That day was a bad day because I want to commit suicide and die. I went to buy poison, but God used my first child to save my life. The child has been monitoring me since I came from the hospital, especially all what I have been doing. I kept the poison in my room, thinking when the child goes to school, I will take it and kill myself. Not know that the child was monitoring me from the house entrance, the following day I went to my room to pick up the poison and take it, but I can't find it until she came from school. She then asked me: 'Mummy, what have you been looking for since morning?' Then, she began to cry saying my mummy wants to commit suicide. If not for that child, I would have died by now. She then advised that I should inform my family about it and request that they take me to the hospital. When I went to the hospital, I saw lots of people living with HIV for long period, and that made me to change my mind about committing suicide.

The HIV onset affected the sense of the participant's post-diagnostic self, in which the quest to commit suicide was the participant's reaction to her HIV diagnosis. The participant's attempted suicide emanated from the loss of will to live with HIV, which is an important ingredient in forging the post-diagnostic self. The moment the participant saw other people living with HIV, the negative cultural understanding of HIV was demystified, and thus helped to regain the will to live with the condition. However, a subsequent account of Nike (a 39-years old woman, living with HIV for eight years) revealed how attempted suicide was the fallout of the cultural understanding of HIV and constituted the important outcome of the post-diagnostic self:

> I had undergone HIV test from three different places confirming that I was positive. Yet, I did not accept those results. All I was saying was that they don't know what they are saying. It was when I did the test the fourth time in a hospital close to my house that I knew all was not well. I felt that the world is meaningless and void. I just felt the world is not worth living at the time. I went mad and I ran out of the hospital and stayed in the middle of a major road that was close to the hospital and I wanted the incoming heavy vehicles to hit me and die. But the trailer (long vehicle) driver applied brake and stopped suddenly. Then the police came and return me to the hospital where I ran out from. That day I just felt that death is better than having HIV. In fact, I nearly committed suicide that day because I prefer to die than to have HIV. I was saying that everything has finished for me, but with encouragement from the

> chairperson of the NGOs that recommended such facility, who supported me and gave me encouragement that the world has not ended, and that I can still live like others if I take my drugs daily. The NGO made sure I was enrolled in State hospital and be placed on drugs. After much counselling from hospital staff, nurses, and doctors, I accepted my fate and I move on with my life.

Like Yemmy, the attempted suicide by Nike was the personal reaction to the HIV diagnosis, and thus constituted the loss of will to live. This attempted suicide is the demonstration of the onset of the post-diagnostic self, that stemmed from the negative cultural understanding about HIV. The sense of post-diagnostic self was activated following the acceptance of HIV after the fourth testing, which subsequently led to the loss of the will to live with HIV. Sustaining the post-diagnostic self was unlikely to ensue if the participant's will to live with HIV was lost completely. Therefore, persuading the participant to eschew the suicide option through counselling and treatment was about regaining the lost will to live with HIV, and to enable the participant to incorporate the condition into her post-diagnostic life and live positively with HIV. It is the acceptance of HIV and the will to live with it, that made the post-diagnostic self to be fully emerged. Without these features, the post-diagnostic self cannot be constructed by people living with HIV.

Having differentiated the pre-diagnostic self from the post-diagnostic self, the question of how the less-valued post-diagnostic self is constructed by HIV-positive individuals following the onset of HIV has remained unaddressed. The construction of the less-valued post-diagnostic self of the participants in this study can be understood through two themes that emerged from participants' narratives: the hopeless self and the powerless self. However, participants as individuals possess multiple identities and selves (Serpe 1987) that stem from their respective social roles they enact and occupy in the society (Tholts 1991). Sometimes, these participants also constructed both the hopeless self and the powerless self, stigmatised unhealthy identities, and switched to either self and identity based on their individual circumstances and conditions. Therefore, the construction of the hopeless self and the powerless self in this study stemmed from the common themes that are observed in the participants' narratives. These themes will now be discussed in the sections below.

7.3.1 Hopeless Self

The emergence of the post-diagnostic self ensued when the participants' previously held assumptions and understandings of the world changed. Becoming hopeless about their situations is one of the changes that HIV brought to the participants' sense of self. This feeling of hopelessness which ensued immediately after HIV diagnosis was entrenched later in the post-diagnostic lives of 13 participants in this study. Being hopeless means a lack of optimism for a better situation or success, cure or remedy for an HIV condition. The narrative of Sida (a 36-year-old woman, living with the HIV for nine years) illustrated how the onset of a post-diagnostic self is characterised by changes in the worldview of HIV-positive individuals:

> I felt so bad when I was told that I have HIV. I even thought of committing suicide and getting out of this world. I felt that the world is meaningless and not worth living at the time… I was tired of the world because HIV is an incurable disease and there was no hope for a cure and survival. I felt so tired that I think everything has ended in my life. My friends have deserted me because of HIV. Now I don't have any friends. I'm a lone ranger. I wish an HIV cure had been found because I'm tired of HIV and tired of taking drugs daily.

The participant's feelings of hopelessness stemmed from the incurable nature of HIV. Consequently, this sense of the participant's post-diagnostic self is shaped by the biomedical explanation of HIV that has been woven into the cultural understanding of HIV in Nigeria. The effects of a diagnostic pronouncement on the participant produces a sense of hopelessness, which can be situated around the stigmatised nature of HIV incurability. The participant's feeling of hopelessness, due to her personal reaction to the stigma around an HIV diagnosis, turned to thoughts of suicide. The self-image emerges out of the reflected appraisal process about who we are (Gecas & Burke 1995), based on direct experiences with the environment and understandings of the world (Stets & Burke 2003). The participant's narrative that 'the world is meaningless' is about the construction of the post-diagnostic self around the feelings of hopelessness associated with the lack of a cure for HIV. Also, the participant's narrative of a meaningless world demonstrated how the construction of a hopeless post-diagnostic self shaped the understanding of an unhealthy identity.

From the narrative above, the participants focused on wanting a cure rather than treatment that can manage the condition. The construction of the hopeless self has more to do with the HIV stigma than the lack of a cure for HIV. Therefore, the stigmatised identity that the participant constructed shortly after her HIV diagnosis impinges on the sense of the hopeless self that was later forged. The HIV identity that was first developed became the new whole in the participant's self. When the post-diagnostic self later emerged, it draws largely from the stigma around HIV. The exclusion by friends due to an HIV disclosure further compounds the worsened sense of the hopeless self and signalled an important shift in the participant's management of HIV in everyday life.

However, the narrative of Kenny (a 48-year-old woman, who has been living with HIV for 12 years) offered a different dimension to the understanding of how a post-diagnostic self was constructed around feelings of hopelessness regarding the cure for HIV:

> When I was diagnosed with HIV, I knew I was not healthy again because I have not been told that the cure for HIV has been found. If the virus remains in my body, I'm still unhealthy. Taking medications daily is just to suppress the virus.

HIV diagnosis does not only change the sense of self, but also disrupts the structure of everyday life (Bury 1982). The consequences of this biographical disruption can be seen in the construction of a hopeless self around the lack of a cure for HIV. The construction of an unhealthy identity represents a significant phase in how the participant's understanding of who she was occurred in the context of her reaction to HIV diagnosis in the post-diagnostic era. Despite the recent biomedical advances in HIV therapy that suppress the virus to an undetectable level and made undetectability as untransmittable (U=U), if the participants still perceive themselves to be unhealthy with the presence of the virus in the body, then undetectability has nothing to do with being unhealthy; rather, it is the cultural inscription of HIV as being unhealthy. Therefore, the unhealthy identity that was constructed around the hopeless self is a cultural marker for a stigmatised identity. The consequences of HIV can be seen in the changes in the self-outlook that the participant constructed and interpreted as the hopeless self due to the lack of a cure for HIV and the stigmatised identity associated with having HIV.

7.3.2 Powerless Self

Following the participants who constructed the hopeless self, there are other participants who constructed the powerless sense of self in the post-diagnostic era of living with HIV. The powerless self is the common theme that featured prominently in the narratives of 19 participants who describe the lack of autonomy and control over a post-diagnostic lifestyle. As part of the changes in the self-image, the feeling of being powerless means the inability to exercise their agencies under certain circumstances, as HIV dictates how the participants live their daily lives. With the powerless self, the participants reported that they are restricted to follow a course of action (dietary/therapeutic requirements) that stripped them of what they perceived to be their real selves. The participants felt that they lacked autonomy, as they were severely prevented from undertaking actions capable of undermining their health and the efficacy of their medication regimen. This sense of powerlessness is the understanding of the new self that participants experienced and constructed in the post-diagnostic management of HIV. The narrative of Mercy (a 41-year-old-woman, living with HIV for nine years) demonstrates how the new self is constructed around a sense of powerlessness:

> The day that I knew about my HIV status seemed like the end of the world to me. I wept profusely that day and I was not comfortable for one week. For the first six months, I was not satisfied with my condition. Due to therapeutic requirements, HIV restricted me from most practices I enjoy most such as partying, drinking, smoking… It is like taking a fish out of the water and expect it to be functional. I'm just sick and tired of this hopeless situation of HIV that I have found myself in.

The feeling of powerlessness that the participant constructed around her new sense of self is based on changes that HIV brought to her life and circumstances (that is, the restrictions that HIV posed to the continuation of a previous lifestyle that was characterised by clubbing, partying, and alcohol use). The inability to adjust to the new circumstances and the lack of control over the new regime that HIV foisted over her lifestyle culminated in the sense of powerlessness, and thus created a new awareness of self that is radically different from the former self. A recent study by Shuper et al. (2010) found that alcohol can worsen the course of the disease and undermine its treatment regimen. Shuper et al. (2010) observed that alcohol affects the immune system and contributes to the worsened course of HIV by affecting the CD_4 count of people with HIV. The restriction of the participant from drinking alcohol, partying, and smoking is part of a social control initiative imposed by healthcare professionals, based on scientific evidence to ensure adherence to a treatment regimen and this was impacting on her sense of self.

Another participant, Johnson (a 57-year-old-man, living with HIV for 12 years), demonstrated how the sense of a powerless self is constructed around the constraints on his autonomy in the post-diagnostic era:

> Before, I smoke cigarettes, marijuana, eat bitter kola and also drink different alcoholic beers and wines, but when I was told during counselling and at a seminar that it will undermine the efficacy of the drugs I am taking, I stopped eating bitter kola. I can’t imagine living my life without alcohol and partying. Life is empty and meaningless without them. I am not satisfied without taking a pint of alcohol. I know myself very well, this is not me. My real self will not agree to eschew this lifestyle without cigarettes and alcohol.

The sense of a powerless self is the meaninglessness associated with the current lifestyle of the participant, which abhors taking substances that can undermine the efficacy of his HIV treatment regimen. The sense of a post-diagnostic self is constructed following the tension between the old habitual lifestyle and the current lifestyle of the participant, orchestrated by the inability to assert his agency due to the lack of satisfaction with the new lifestyle requirements imposed by his HIV condition. Although the HIV condition does not control the lifestyle of the participants, it is the participants that are making these changes based on their understanding and the advice they have received. The changes that these participants made in terms of lifestyle are reflected in the tension between agency and choice, that now becomes the important part of the post-diagnostic self.

By making a comparison between past practices and current reality, HIV serves as a reminder to the participant that the new health regime requires a compliance towards a specific lifestyle that is fundamentally different from the previous way of living. Having the sense that something is missing in the participant’s life is the feeling of powerlessness to engage in whatever practices and type of lifestyle is required without worsening his HIV condition. It is this reminder that there is a limit to which HIV-positive individuals can go as far as the threat posed by HIV is concerned, and that limit activates the sense of a new self around feelings of powerlessness that participants constructed. The sense of a powerless self is demonstrated by the changes in the way in which participants understand changes in their self-image in comparison with the pre-HIV era because of a restricted lifestyle over therapeutic requirements.

However, the participants’ construction of a post-diagnostic self around hopeless and powerless selves is the expression of the less-valued self that emanated following HIV diagnosis. Furthermore, these constructions demonstrate changes that had occurred in the participants’ self-image from the pre-diagnosis period to the post-diagnosis period, which highlights the onset of the post-diagnostic self in an HIV context. It is the extreme versions of hopelessness and powerlessness that would facilitate the loss of the will to live.

Without the will to live with the condition, death could be imminent as there would be no resilience for participants who constructed the extreme versions of hopeless and powerless selves to prevent their conditions from developing into suicidal thoughts. In this sense, therefore, these constructions of the post-diagnostic selves by the participants require the will to live with the condition for effective management of a chronic illness condition like HIV to occur.

Having understood how the post-diagnostic self is formed and constructed, the other central question in this chapter about the impact of healthwork on the sense of self requires further exploration. This question will be explored in section 7.4 below.

7.4 The impact of healthwork on the sense of self in an HIV context

In contrast to Charmaz’s (1983) argument that chronically ill patients are reconstructing their lost self, the chronically ill patients are not reconstructing their lost aspect of the pre-diagnostic self. This is because the retained part of the pre-diagnostic self has already become part of the post-diagnostic self and constituted part of the changes in the biography. The chronically ill patients are trying to regain the lost aspect of the pre-diagnostic self, and not the pre-diagnostic self per se. Even if the chronically ill patients are able to regain part of their pre-diagnostic self, their sense of self cannot return to the initial pre-diagnostic self. Therefore, any regained aspect of the pre-diagnostic self would always form part of the post-diagnostic self.

The development of the post-diagnostic self cannot fully occur without the help of actions and activities that are within and outside the normal daily routine of the patients (Hyden 1997), which represents healthwork in this thesis. For instance, the stability of the post-diagnostic self requires the components of healthwork such as counselling, testing, adherence and, sometimes, concealment. In this sense, the relationship between healthwork and the post-diagnostic self stems from the roles of the former in shaping the latter.

From the narratives of the participants, two categories emerged about the role that healthwork plays in shaping the post-diagnostic self of people living with HIV. These categories, which are the empowered self and the optimistic self, will now be examined in the sections that follow.

7.4.1 Empowered self

Following HIV diagnosis, healthwork helps the participants with the powerless sense of self to effectively manage their everyday life. From the narratives of the participants, one way in which healthwork shapes the powerless sense of self in a positive way is through empowerment. With empowerment, healthwork offers the participants an empowered self to deal with their sense of powerlessness. Empowerment here is the confidence and sense of being in control of one's life. With an empowered self, adherence enabled the participants to construct a semblance of control and power over their lives and how they see themselves, by bracketing off aspects of their lives they were deemed to be powerless over.

The narrative of Bose (a 35-year-old woman, living with HIV for 10 years), demonstrated how healthwork empowers her to cope with the new health regime of HIV:

> When I was diagnosed with HIV, the doctor told me that there was no problem if I follow all the medical instructions. Now, occasionally I go to a party and I stopped smoking cigarettes and cocaine. Sometimes, HIV could be a blessing in disguise because, without HIV, I won't stop that kind of lifestyle. HIV has indeed humbled me and following the doctor's instructions and taking my drugs regularly has given me the power to control my appetite for partying and smoking of cigarettes and cocaine, but I have not stopped taking alcohol completely. Once in a month, I still take two to three bottles at home. I'm a changed person now and people in my street are now relating with me as a responsible person, unlike in the past.

With an empowered self, healthwork enabled the participants to deal with their experience of a powerless self. The component of healthwork utilised to foster and empower the participant's self in the narrative above is adherence, and adherence empowers the post-diagnostic self of the participant to bracket off a sense of powerlessness associated with a loss of control over smoking of cigarettes and cocaine, habits that are foregone to achieve treatment efficacy. Despite the experience of powerlessness, healthwork is enabling the participants to construct positivity around their selves, by considering their current lifestyles as more empowering than the previous lifestyles that were lost to HIV.

Subsequently, the narrative of another participant, Ade (a 48-year-old man, living with HIV for seven years), further provided insight into how healthwork offers an empowered self to the participants in the HIV context:

> Prior to HIV diagnosis, I was living a rough life of taking alcohol, smoking, dating different women, and sometimes I don't see my wife and children for days whenever I wanted to go for a partying spree. When my wife and I were diagnosed with HIV, I was unhappy when the doctor told me that HIV medications cannot work together with alcohol, herbs, and smoking cigarettes. Following medical instructions has helped me to get a grip over my life, live a normal life and abandon my past way of rough living. Now my wife could not believe that I can be sober, gentle, and changed for the good.

The participants who constructed a powerless sense of self reflected on their past selves in a way that makes them think that they lacked power in the past, even though they thought that had autonomy. The participants felt powerless after their diagnosis, and that sense of a powerless self was precipitated by the contrasting tension between the participants' lifestyle and contracting HIV. Like other participants with a powerless self, the narrative of Ade demonstrates how healthwork helps to offer a sense of control over his life. The powerless sense of self was later mitigated by the components of healthwork—adherence and counselling—which enabled empowerment to take place. Like Bose, the loss of a potential gain in living a rough life of taking alcohol, smoking cigarettes and excessive partying was offset by abandonment that involves taking control over a way of life that was regarded as abnormal. The role of healthwork is pivotal towards empowering the participant's powerless self to take active control and having autonomy over his life and affairs. With an empowered self, the participants possessed a greater sense of taking autonomy and control over their lives vis-à-vis adherence and counselling, the consequences of which are nothing compared with the health implications of the alternative, which would be to continue with a previous damaging lifestyle.

Generally, the reaction to being diagnosed with HIV marks the construction of the powerless self. The findings in this chapter have revealed that healthwork (through adherence and counselling) offers an empowered self to the participants, with a powerless sense of self to be able to take control of their lives in areas where the alternative to their powerlessness can be achieved.

7.4.2 Optimistic self

Following HIV diagnosis, healthwork helps the participants to manage their hopeless sense of self effectively. Without healthwork, participants might lose their will to live and this could trigger suicidal thoughts or lead them to seeking a medically assisted death. The optimistic self emerged as one of the important themes that underpinned how healthwork helps to shape the sense of self of participants with a hopeless self. In other words, healthwork offers a sense of optimism to the participants who experienced a hopeless self.

The sense of optimism is about giving hope where the participants' conditions were constructed as being hopeless. With an optimistic self, healthwork is helping to prepare the sense of self of the participants to be confident, hopeful, and to have a positive view about their situation. This will enable them not only to cope with their conditions but contribute to the everyday management of HIV. The account of Sattu (a 30-year-old woman, living with HIV for five years) evidently demonstrated this position:

> Initially, I was hopeless because there is no cure for HIV and I'm the kind of person that resents taking drugs, not to talk of living on drugs for the rest of my life. When I check my viral load and it was undetectable, I was happy and hopeful that an HIV cure will soon be found.

Through testing, healthwork was able to provide an optimistic self to the participant and made her hopeful about the future of HIV, despite the initial sense of hopelessness. Achieving undetectability not only ushers a sense of optimism about the efficacy of the medications, but also provides hope that the cure for HIV could be imminent. The components of healthwork that were utilised are adherence and testing, and these components enabled the participant to see a positive outcome in negative developments that coalescence around the lack of a cure for HIV.

Subsequently, the narrative of Sida (a 36-year-old-woman, living with HIV for nine years) further revealed how healthwork has enabled the participant to construct the sense of an optimistic self to act as a bulwark against disenchantment associated with a hopeless sense of self:

> One of the reasons why I was in despair about HIV is because there is no cure for it. When we are told in support group meetings that, after a few years of taking medications, HIV will not be detected in our blood, immediately I said it is not possible. But when a few members of the support group said that their viral load shows undetectable and don't know whether to continue taking the medication or not, then I was optimistic that one day an HIV cure may be found.

Healthwork provides hope and optimism for the participant to navigate beyond the sense of a hopeless self that was constructed around the lack of HIV curative medications. Awareness of HIV undetectability from the support group members made the participant optimistic about a possible cure for HIV being found, even when the feelings of hopelessness were still being constructed. Support group participation as a component of healthwork was instrumental in forging a sense of optimism for the participant, but insufficient to remove the participant's doubt about the lack of HIV cure associated with a hopeless self. Healthwork, therefore, helps to delegitimise the hopeless self by providing optimism for the participant to continue treatment and the daily management of HIV, to keep faith and hope in the treatment and its ability to restore health and normalise their conditions, and to avoid feelings of hopelessness that can worsen their existing health conditions.

Another participant, Bimbo (a 38-year-old-woman, living with HIV for 10 years), demonstrated how spirituality helped to construct an optimistic self in the post-diagnostic epoch of HIV management:

> Despite taking these drugs regularly, I always go to church and pray about this condition. I know that God can do anything, and I know that God will raise up scientists that will find solutions to this HIV issue one day.

With adherence, another dimension through which healthwork offers an optimistic self to the participants with a hopeless self is spirituality. From the narrative of Bimbo, spirituality offers an optimistic self that enabled the participant to regain hope of an HIV cure from the initial sense of hopelessness. With spirituality, the optimistic self helps to make a smooth transition to the post-diagnostic period for the participants with a hopeless self to be hopeful and ensures that their daily living with HIV can be more tolerable. Despite the effective treatment regime, finding a cure for the participant might be more important because of the wider cultural understanding and stigmatised identity. Therefore, what made the optimistic self necessary for the participant might be the hope of finding an HIV cure to navigate away from the cultural understanding of HIV that underpinned a stigmatised identity.

Generally, this study's finding has unpacked how healthwork has helped the participants to shape their new selves in two ways: through an empowered self and an optimistic self. It was further revealed that adherence, counselling, spirituality, and support group participation are utilised by the participants as important components of healthwork to shape and reshape the post-diagnostic self as far as HIV management is concerned. In this study, it was found that counselling is the common element of healthwork utilised in providing empowerment and forging the optimism needed for the post-diagnostic self to be sustainable in the daily management of HIV. Without healthwork, the sense of a powerless self and a hopeless self can rapidly translate into disenchantment about the world and facilitate the participants' loss of the will to live with HIV.

For instance, the narratives of Praise (a 52-year-old-woman, living with HIV for 27 years) demonstrated how healthwork helped to prevent hopelessness or a hopeless self from sliding into the participant's loss of the will to live with HIV:

> There are times that I refused to take my medications... because I don't have hope about it any longer. In fact, I have done that more than three times now. There was a night that I just look at the drugs and keep it somewhere, but my children who are watching me, asked why I don't want to take these drugs. I told them that I am fed up with the drugs and that I have stopped taking it for three weeks. My children were crying, and they had to call my grandmother and family members, who came to appeal to me to continue taking the drugs. My family members went as far as my workplace at the state hospital and informed my boss and other colleagues who are HIV counsellors, who came and started appealing to me about the danger of the virus developing resistance to drugs and how my condition can quickly be translated into AIDS and death. My family even brought my pastor, who prayed, counselled, and talked to me extensively. After many pleas from these people, I started taking the medications again.

The combination of counselling and spirituality helped to prevent the hopelessness of Praise from translating into the loss of the will to live with the condition. The consequence of the loss of the will to live might be a lack of engagement in healthwork, especially adherence, which could further imply that the virus develops resistance, weakens the immune system, and affects the ability to fight opportunistic infections; subsequently, the conditions develop into AIDS. Other potential consequences of the loss of the will to live might be suicidal thoughts, resorting to suicidal acts or seeking medically assisted death.

Unlike Praise, whose healthwork helped to prevent her sense of hopelessness from sliding into the loss of the will to live, the narrative of Davis (a 58-year-old-man, living with HIV for 11 years) demonstrated how healthwork prevented the transition to the loss of the will to live, arising from the sense of powerlessness:

> When I started taking these medications, they said I should not eat bitter kola, drink alcohol, use local herbs, and engage in practices that could compromise my health. Having followed that for more than four years, one day I was just fed up and I started taking herbs, alcohol and eating bitter kola. I'm the one that is supposed to control HIV, not HIV controlling me. The following week I received a check-up call from one of the nurses and I told her that I have stopped taking the drugs for one week. The following day, she came with three other hospital staff who counselled and persuaded me to continue to take my medications.

The deliberate act of non-adherence on the part of the participant demonstrated how a sense of powerlessness can be translated into the loss of the will to live. Counselling played an important role in helping to get the participant to return to treatment or start taking medications again. Otherwise, continuous non-adherence as in Praise's case could lead to viral resistance, the onset of opportunistic infections, and the transition of HIV into AIDS. In extreme cases, the loss of the will to live could lead to suicide or seeking a medically assisted death.

Without healthwork that can offer an empowered and optimistic sense of self to the participants, HIV-positive individuals give up on their conditions and stop taking their antiretroviral medications. This means that ill persons have nothing else to live for and, hence, lose interest in fighting for their health and life. The consequence that can ensue is that suicide/death could be considered as more honourable than living in a hopeless and powerless world. In this case, unless something happens to encourage them to start taking their medication again, the eventuality of death or suicide is anticipated.

7.5 Conclusion

This chapter has sought to explore the impact of HIV and the associated healthwork on the self of people living with the condition. As we have seen, the study has expanded Charmaz's notion of self in chronic illness by reconceptualising self as a pre-diagnostic self and a post-diagnostic self in an HIV context. The onset of chronic illness alters and disrupts the pre-diagnostic self of the participants and results in the loss of some aspects of the pre-diagnostic self. The remaining aspect of the pre-diagnostic self that was not affected by HIV disruption is the less-valued self that later constitutes part of the post-diagnostic self. The post-diagnostic self that emerged out of the fallout from the onset of a chronic illness, and which can change and fluctuate over time, is the self that accommodates the illness into the everyday lives of the people living with HIV. The transition to a post-diagnostic self involves the less-valued self and the will to live with the condition.

The observations about how participants constructed their post-diagnostic selves around a hopeless self and a powerless self are consequences of the changes in self that HIV onset brought to their everyday lives. Together with the will to live with the condition, these constructions have not only revealed what constitutes the post-diagnostic self, but have demonstrated the changes that occurred, or which facilitated the transition to the post-diagnostic self in an HIV context. This construction of a hopeless self and a powerless self is the less-valued self that Charmaz (1983) observed, and this finding further confirmed the observations in other studies (Charmaz 1987; 1991; 1994; 1995; 1999; 2000; Corbin & Strauss 1987; Radley 1989; Kelly 1992; Kelly & Field 1996; Pierret 2003) on self in HIV and other chronic illnesses.

The consequences of the loss of self that Charmaz (1983: 168) observed in the form of 'leading restricted lives, experiencing social isolation, being discredited and burdening others' are the less-valued self or forms of the post-diagnostic self, as evidenced by the hopeless self and the powerless self in this study. This study therefore expands on Charmaz's conception of self in chronic illness, by conceptualising the self around the pre-diagnostic self and the post-diagnostic self. This conceptualisation helps to understand how the remaining aspect of the pre-diagnostic self, coupled with the will to live with the condition, constituted part of the post-diagnostic self. The demonstration of the transition from the pre-diagnostic self to the post-diagnostic self is the significant contribution and expansion that this study has added to Charmaz's articulation.

Nevertheless, this study and that of Charmaz differs in two ways. The first is in the context of the post-diagnostic self that becomes the basis through which chronic illness is incorporated into the everyday life of the patients. Charmaz's study did not address the will to live with the condition as an important part of the self in the post-diagnostic lives of chronically ill individuals. The remaining aspect of the pre-diagnostic self is not capable of sustaining the post-diagnostic way of living with chronic illness and Charmaz's work did not address this. Without the will to live with the condition, there will be no basis for self in the post-diagnostic era. The will to live is the orientation of the post-diagnostic self towards striving for survival. The transition to the post-diagnostic self will be concluded when chronically ill individuals have inculcated the quest for survival into the fabric of their lives. This aspect of the post-diagnostic self that was obscured in Charmaz's work has now been addressed in this study.

The second is the contextual difference that made the understanding of chronic illnesses different. Charmaz's work is purely Western in its focus. This study, however, is rooted in a Nigerian context, where consequences of African culture and traditions on the understanding of health and illness have a different impact on patients' sense of self. Therefore, Charmaz's articulation cannot be effectively applied to a cultural understanding of health and illness in Nigeria, which therefore has significant implications on how HIV-positive individuals construct their sense of self in an illness context.

Despite these differences between my research and that of Charmaz, there are two areas where similarity exists in both studies. First, Charmaz's (1994) observation that the chronically ill are either preserving their selves or recapturing their past selves is being shared by this study's findings. This is because chronic illness fundamentally alters the sense of self of the participants, but such an alteration only leads to a less-valued self that constitutes changes in self-images and facilitates the onset of the post-diagnostic self that may change over time. The second is that both studies focused on the primary assault of the chronic illness on the self. Charmaz's study, on the other hand, focused more on some chronic illnesses that have bodily effects and physical debilitations on the patients. Yet, the primary assault on the self relates to the stigma that became the consequence of physical debilitations that a chronic illness posed on the patients' bodies, and the culturally imposed stigma that the onset of HIV has on the participants' self and identity, despite not experiencing physical debilitations like other chronic conditions.

Subsequently, the comparison between this study and previous studies revealed different understandings of self in chronic illness. This is because self in previous studies is defined in generic terms, without specifying what kind of self was altered by HIV and other chronic illnesses and what kind of self that emerged following the onset of chronic illness. The onset of a chronic illness does not facilitate the complete loss of self, but a transition from the pre-diagnostic self to the post-diagnostic self as earlier stated.

The finding in this study is in contrast with Freeman's (2016) research on identity work, which depicts identifying and accepting aspects of self that were lost through illness and diagnosis, with a view to reclaiming those aspects so that the self is recreated or redefined to incorporate HIV (Freeman 2017: 712). A further difference in this study, when compared with Freeman's work, is the understanding that the post-diagnostic self has already incorporated HIV with retained/remaining aspects of the pre-diagnostic self, and that it is the post-diagnostic self that can facilitate identity work or identity control. Finally, that HIV identity impacted on the sense of the post-diagnostic self, not self as generically utilised in the study.

However, the articulation of both the pre-diagnostic and the post-diagnostic self is an attempt to expand and refigure ways in which the self in a chronic illness has traditionally been understood. This is necessary following a significant shift in the understanding of self in chronic illness more than 30 years after Charmaz articulated it, coupled with the advancement in treatment of chronic illnesses, especially HIV, in the twenty-first century. This expansion, refiguration, and reconceptualisation of self is not about redrawing the intellectual map or tampering with disputed borders as Geertz (1980) argued, but altering and changing the basis through which the self in chronic illness is understood, interpreted, and analysed. This refiguration has afforded us the opportunity to recast the self in a new light and flesh out the challenges facing the post-diagnostic self, if not properly managed and sustained, which could be the loss of the will to live and recourse to suicidal thoughts, leading to death. With changes in the self from the pre-diagnostic self to the post-diagnostic self, the findings revealed that healthwork provides a sense of empowered and optimistic selves for HIV-positive individuals and enables their sense of the post-diagnostic self to effectively manage HIV in everyday life. The implications of this finding have opened a new analytical and empirical pathway towards understanding how suicide can ensue, if the chronically ill person lose their will to live with their conditions in post-diagnostic epoch.

Since self cannot be analysed without identity, the findings in this study revealed that the onset of HIV heralded the onset of a new identity (which is an HIV identity) that is woven into the post-diagnostic self. It was further revealed that this new HIV identity was constructed around stigmatised and unhealthy identities based on the societal understanding, or cultural understanding and response, to HIV in the Nigerian context. This finding on the stigmatised identity found empirical support in previous studies that confirmed that HIV-positive people with a stigmatised identity have become standard bearers of ‘spoiled identity’ due to their medical condition and cultural understanding of HIV (Tewksbury 1994; Alonzo & Reynolds 1995; Tewksbury & McGaughey 1997).

Furthermore, it was found that these constructed stigmatised and unhealthy identities not only shaped but became the basis through which the participants constructed their sense of a hopeless and a powerless self. Following the emergence of these identities, it was revealed that healthwork plays an important role in ensuring that HIV is woven into the everyday life of people living with HIV with an empowered self and an optimistic self. The findings on self and identity in this study further demonstrate the way in which the structural element (healthwork) shapes biographical issues (self/identity) and, therefore, have implications for chronic illness management in healthcare practices.

This finding, which has helped to address the question of the impact of healthwork on the sense of self, has further helped to address this gap in the literature. Finally, the self forms the basis of everyday experiences and the core aspects of the everyday experience of illness (Kelly & Field 1996). Therefore, effective management of a chronic condition like HIV requires effective management of the post-diagnostic self through continued healthwork practices.

CHAPTER EIGHT

DISCUSSION AND CONCLUSION

8.1 Introduction

The aim of this study was to understand the biographical implications of healthwork on the everyday lives of people living with HIV. This research has built on previous research on healthwork (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008) and biographical work (Corbin & Strauss 1987; 1988; Faircloth et al. 2004) by exploring the consequences of healthwork on the biographies of HIV-positive individuals. Within this study, the impact of healthwork on the three main components of biography or the BBC chain, as outlined by Corbin and Strauss (1987), have been explored: biographical time, the body, and the conception of self.

Thirty-two heterosexual men and women recruited from two HIV-support groups in Nigeria were interviewed about their experiences of HIV diagnosis, treatment and the healthwork they undertake as part of HIV management in their everyday lives. Through a qualitative methodological approach and a semi-structured interviewing process, valuable data was gathered that offered insight into the kind of activities and practices that people living with HIV undertook around their health and how this had impacts on their biographies in everyday life. It was observed in this thesis that HIV disrupted the biographies of people living with HIV. The consequences of HIV on the participants are the effects of the disruption caused to the BBC chain of the participants. The consequences of HIV disruption, as observed in this study, have resulted in the redirection and discontinuity in the biographical temporality; an experience of otherness, dirty and infectious senses of corporealities; forging of hopeless and powerless sense of self; and having a sense of a stigmatised and unhealthy identity. This finding agrees with similar empirical findings from studies that have explored how chronic illness constituted disruptive events and episodes in the daily lives of chronically ill patients (Bury 1982; Faircloth et al. 2004; Wilson 2007; Reeve et al. 2010; Locock & Ziébland 2015; Sveen et al. 2016).

Other summaries of this research are highlighted as part of the contributions to the sociological knowledge in section 8.2. The outline of the rest of this chapter is as follows: the limitations of this study are explored in section in 8.3; section 8.4

addresses the implications of these findings for further research; and concluding remarks are detailed in section 8.5.

8.2 Key Contributions

In this section, the key contributions of this research to the sociological knowledge are summarised. This study has contributed to sociological knowledge in five significant ways, and these contributions are presented below.

First, the overall contribution of this study is that healthwork involves a kind of post-diagnostic practices initiated by HIV-positive individuals to reconstruct and reconstitute their disrupted biographies and restore the broken BBC chain. In this regard, healthwork displaces biographical work as a strategy of reconstituting the disrupted biographies of people living with HIV following HIV diagnosis. This is because adherence, counselling, testing, spirituality, and support group participation are practices of healthwork that are used to facilitate biographical reconstitution through continuity and positivity (to the disrupted biographical temporality); reassessment, negotiation, minimisation, and demythologisation (to the disrupted sense of corporeality); and empowered self and optimistic self (to the disrupted sense of self). These practices are the practices around the participants' biographies, which are undertaken holistically and simultaneously. Furthermore, these practices of healthwork have demonstrated that biographical reconstitution requires the mobilisation of internal and external practices to restore stability to the disruptions brought by HIV diagnosis. This finding demonstrates the relevance of the BBC framework, as it is central to biographical reconstitution that healthwork facilitates. In other words, the relevance of the BBC chain is reflected in understanding the components of biographies disrupted by HIV diagnosis; how they were disrupted; and how healthwork has helped to rebuild and reconstitute these disrupted biographical components in the HIV context.

However, this finding contrasts with the observation of Corbin and Strauss (Corbin & Strauss 1987; 1988) and other studies (Robinson 1988; Boeije et al. 2002; Fischer-Rosenthal 2002; Clarke et al. 2003; Faircloth 2004; Ville 2005; Felde 2011; Hesse 2019) that argued that biographical work (through accommodation) is the basis of biographical reconstitution in chronic illness management. This study rather found that HIV was accommodated into the fabric of their lives through the internal practices of adherence, concealment, dieting and spirituality, but such accommodation was not enough to facilitate biographical reconstitution in HIV management without the imprimatur of external practices like counselling, testing, and support group participation. This finding makes an important contribution by expanding the works of Corbin and Strauss, and other scholars on chronic illness management to incorporate external practices to supplement internal practices in HIV management. Therefore, healthwork displaces biographical work as a way of biographical reconstitution in HIV management.

The second contribution is that healthwork also helps to deepen the close interconnection between the different elements of the BBC chain. The impact of healthwork on one element of the BBC chain have effects on other elements of the BBC chain. Reconstituting biographies here involves bringing together different elements of the BBC chain that have been disrupted, such that the impact of healthwork on one element of the BBC chain that has effects on other elements. There are two examples which demonstrated this most profoundly. First, the sense of hopelessness and powerlessness might not only relate to the loss of control and lack of a cure for HIV but also the sense of discontinuity and uncertainty experienced in a person’s biographical temporality. The sense of hopelessness might be the inability to be cured which could help patients save their marriage or rescue their life ambitions and careers from an uncertain future or being discontinued.

The sense of hopelessness could have been translated into powerlessness as the participants might feel they lack the power or ability to control the tide of HIV disruption to their biographical temporalities. Therefore, the use of healthwork to repair and reconstruct their disrupted biography towards reorganisation and resumption could have effects on the hopeless self and the powerless self. This is because the optimism and empowerment, which healthwork offered to the participants’ sense of hopelessness and powerlessness serve, as the impetus used in the reorganisation and resumption of their disrupted biographical temporalities. In this regard, healthwork provided not only empowerment but optimism for the participants to confidently repair and reconstruct their disrupted biographies by transforming redirection and discontinuity to reorganisation and resumption. Second, HIV disrupts the corporeal sense of the participants, by ushering in otherness, dirty and infectious corporealities. The effect of HIV disruption on corporeality impinges on the participants' sense of identification as stigmatised and unhealthy identities. The more people living with HIV consider themselves as others due to HIV infections or as having a dirty corporeality, the more they appropriate a stigmatised identity.

Furthermore, the more HIV-positive individuals regarded themselves as having an infectious corporeality, the more they appropriate an unhealthy identity. Therefore, HIV disrupted not only the corporeal sense and identity of participants but ushered in new forms of relationship between the body and identity, which Strong (1996) regarded as ''appropriation''. Strong elaborated the notion of appropriation as something that was appropriated when individuals possess it, especially 'in a manner that I feel comfortable with, that is in a manner to which the challenges of others will carry little or no significance' (Strong 1996, 125). Expanding Strong's argument, appropriation in this context is the appropriation of corporealities and identities associated with having HIV. The more the people living with HIV appropriate a positive or negative corporeality, the more they identify with an identity associated with such a corporeality.

The impact of healthwork can be seen in relation to how it helps to deepen this pattern of an appropriated relationship, as its effect on one element is reflected in another. The use of healthwork in reconstructing otherness, dirty and infectious corporealities also impacts on the sense of stigmatised and unhealthy identities in appropriated ways. The impact of healthwork in fostering normalisation and partial normalisation could enable the participants to reassess their corporealities as less harmful and then appropriate healthy identities. Furthermore, the use of healthwork to reconstruct otherness and dirty corporealities around minimisation and demythologisation helped to reduce the enacted stigma (stigmatised identity) in their social life and deconstruct the myth of a religiously induced dirty sense of corporeality.

Since biography constitutes a gap in the conceptualisation of healthwork, the expansion of healthwork to incorporate biography through the framework of the BBC chain represents a significant watershed in the analysis of healthwork in HIV management. This finding offers an important contribution by expanding the frontier of healthwork beyond the conceptualisation of Mykhalovskiy and his colleagues, as the basis of forging the interconnection between the different elements of the BBC chain. Therefore, healthwork did not only help to reconstruct and repair the disrupted elements of the BBC chain but also fostered the connections among these elements and deepened the patterns of appropriation inherent in their relationships in a holistic way.

The third contribution of this study to sociological knowledge is that adherence is central to the practice of healthwork in HIV management and constitutes its most important component. Without adherence, the lived experience of HIV is impossible, and the practices of other components of healthwork are unrealistic. Even though adherence is important, it does not tell the whole story about the daily lives of people living with HIV, as there are other practices that people living with HIV perform around treatment that are more encompassing than adherence or of which adherence is a part. This finding aligns with the positions of early sociological works (Stimson 1974; Zola 1981; Trostle et al. 1983; Conrad 1985; Hunt et al. 1989; Donovan & Blake 1992; Turner 1995) that there are other practices that patients perform other than adherence. The difference between this study's findings and that of previous sociological studies is the centrality of adherence in self-governance (governmentality of free ART programmes and technologies-of-the-self), where the individual responsibility and obligation to a healthy body become instrumental in enabling healthwork to reconstitute the disrupted biographies of people living with HIV. This finding has revealed that adherence is pivotal in the self-regulation of the body in producing subjects (HIV patients), whose goals are oriented towards health maintenance, viral suppression, achieving undetectability, and attaining a healthy body.

Nevertheless, healthwork is more encompassing than adherence, as the most important practice for people living with HIV, to support their treatment in daily life. These practices which include spirituality, testing, counselling, concealment, adherence, dieting, support group participation, and Internet use are prevalent in the Nigerian context and are integrated into the biographies of HIV-positive individuals. The implications of this finding demonstrated that healthwork is rooted and integrated into the biographies of the people living with HIV and central to their everyday lives.

This finding broadly aligns with the studies of Mykhalovskiy and his colleagues (Mykhalovskiy & McCoy 2002; Mykhalovskiy et al. 2004; Mykhalovskiy 2008) that healthwork is utilised to support treatment in Canada in the same way that it was in Nigeria. What is fundamentally different between the current study and that of Mykhalovskiy and his colleagues is in the way in which healthwork was undertaken. In the Nigerian context, the participants engaged in the practices of healthwork through spirituality, testing, counselling, concealment, adherence, dieting, support group participation, and Internet use. Whereas in the Canadian context, healthwork is undertaken around 'how people living with HIV obtain their medications, how they translate medical instructions into medication routines and modify those routines in the ongoing flux of their day-to-day lives, and how they recognize pill time' (Mykhalovskiy & McCoy 2002, 24). The findings in this study support the original definition of healthwork, while highlighting cultural differences. Therefore, the critical expansion and extension of healthwork, framed within a specific cultural context and practice, and how healthwork is shaped by and manifested in the Nigerian cultural milieu form an important contribution of this study.

Fourthly, this study has demonstrated that the impacts of HAART and healthwork can help foster longevity, stability, and continuity in the biography and the experience of living with HIV by removing worries and uncertainty associated with imminent death following HIV diagnosis, which had been observed by Weltz (1989), Pierret (1992) and Pierret (2000) in the pre-HAART era. This finding makes an important contribution by demonstrating that the impacts of HAART and healthwork helped to buoy hope, optimism, and positive expectations, as participants regarded undetectability as related to cure. By facilitating normalisation and partial normalisation through effective antiretroviral treatment, healthwork ushered in high hopes and expectations from the participants that undetectability is going to facilitate a cure. Even though attaining undetectability is not a functional cure, healthwork has fostered a new lease of expectations about antiretroviral therapy and the creation of a new reality that tends to overestimate the practical capabilities of biomedical technologies beyond its present value. It has been theorised that people living with HIV aspire to attain HIV undetectability for two reasons.

The first is the belief that undetectability is the path to a future cure for HIV, as attaining undetectability means being closer to cure. The second is that undetectability provided the participants with mental fortitude to escape the infectious and stigmatised characterisations of HIV that feature intensely in cultural and social imaginations. This demonstrates that participants are not predominantly concerned about the hyped visions of medical technology like ART, as emphasized by scholars in the sociology of expectations (Brown 2003; Brown & Michael 2003; Hedgecoe 2003, 2004; Hedgecoe & Martin 2003; Hopkins et al. 2006; Hackett et al. 2007; Hedgecoe & Martin 2007; Pieri 2009), but the role that the hype around medical technology plays in daily life to mitigate the cultural, infectious, and social consequences of health conditions. This finding offers an important contribution that could expand the scope of the sociology of expectations (especially in science and technology studies) to incorporate the social meanings of expectations in medical technology like ART.

The final contribution of this study is that healthwork helps to prevent suicide, as the lack of empowerment and optimism would have resulted in the loss of the will to live with HIV by the participants. This finding offers a new contribution to the sociological discourse on suicide and is a radical departure from classical sociological thought that was dominated by two theoretical traditions: Durkheimian tradition and ethnomethodology. This finding does not align with the Durkheimian/positivistic explanation of social integration and control in understanding why people commit suicide (Pope 1975; Stack 1979; Lester & Abe 1998; Tartaro & Lester 2005) or interested in social construction of suicide from coroner’s interpretations or assumptions (Douglas 1967; Gibbs & Martin 1968; Atkinson 1983). Rather, the finding considered suicide from a health-related perspective, by locating the primacy of the self in understanding suicide in the context of chronic illness.

This finding broadly connects with the contemporary works on suicide that focus on euthanasia or assisted death/suicide. The use of medicine to hasten or procure the death of a patient (who is suffering from an incurable or painful illness) through painless killing by physicians, which is regarded as euthanasia or assisted death/suicide, has been subject of interest to sociologists (Howart & Jeffreys 1996; Muschert 2006; Minocha at al. 2011; Jupp 2016; Richards 2017; Fitzpatrick et al. 2021). The sociological approach to euthanasia or assisted death/suicide has been limited to exploring the ethical issues with euthanasia (Callahan 1994; DeVries 1995); its legality and legalisation (Pakes 2005; Weyers 2006; Seale 2010; Sperling 2019); and beliefs, knowledge and attitudes towards euthanasia (Sharp 2006; Moulton et al. 2006; Cohen et al. 2006; Sikora & Lewins 2007; Wasserman et al. 2005; 2006; Halman & Van Ingen 2015; Francis et al. 2020), with scanty research examining why patients seek assisted death/suicide (Richards & Rotter 2013; Stavrianakis 2020). The lack of an empowered and optimistic sense of self observed in this study could help to unpack the centrality of self as the important factor in explaining why patients might seek for assisted death/suicide. This would expand the knowledge domain beyond these classical traditions and connect with the contemporary works on euthanasia or assisted death/suicide. This finding makes an important contribution in providing a new theoretical framework for empirical research on suicide in the health and illness context.

Overall, this study sought to explore the main research question about the consequences of healthwork on the biographies of people living with HIV in the Nigerian context. What underlies this question is the lack of engagement with how HIV disrupts the biography and the elements of the BBC chain of people living with HIV, and what constitutes healthwork in HIV management. The rationale for conducting this research was the dearth of research in these domains since the development of HAART and exploring the relevance of healthwork and other elements of the BBC chain in a non-Western context, and more specifically a Nigerian context. The contribution of this study therefore helps to fill this gap by adding more depth to the existing knowledge of the sociology of chronic illness and expands the boundary of sociological knowledge of the impact of healthwork on biographical disruptions, biographical work, self and identity in HIV and other chronic illness contexts conducted by previous scholars in this domain. These contributions highlight the issue that has not been considered relevant in the Western literature on healthwork and biography in HIV context. In conclusion, these findings have further deepened the understanding of the biographical implications of healthwork on everyday lives of HIV-positive individuals, and subsequently, answers the overall research question in this thesis.

8.3 Limitations of the research

Despite these key findings, this study has a number of limitations. The first limitation of this research is that an exploration of the gendered experience of HIV management and healthwork was not conducted in this thesis. Gender differences stem from how HIV affects both men and women to varying degrees and in different ways, and how these differences in men's and women's perceptions, decision-making and behaviours could be responsible for different research outcomes and findings. Furthermore, situating gender in this thesis could have shaped the methodology, and impacted the interviewing process, the data collected, and also the findings of this study, and the consequences could have revealed how gender shapes male and female participants' response to HIV in terms of their experience of healthwork, and provided insights into gendered experiences of biography, healthwork and HIV management.

The second is about the sampling, and the way that the sampling frame was developed. The sampling frame for this qualitative research is not representative of the larger Nigerian population. The sample is more indicative of people living with HIV in support groups rather than the broader population of people living with HIV across the country as previously stated. Therefore, recruiting from support groups can lead to a sample skewed towards certain demographical characteristics like those living in urban centres (as in the case of this study's location) and excluded people living in rural areas. Recruiting participants from a wide pool of HIV support groups across the country might serve to broaden the diversity. Yet, financial constraints on the part of the researcher; a lack of interest in participating from other support groups and their members; and a bureaucratic bottleneck inhibiting access and recruitment from government hospitals limited the recruitment for this research to two HIV support groups who were willing to participate. In this regard, the findings in this study do not cover those who do not attend HIV support groups.

The third way in which this research could be considered limited is the generalisability of its findings. Following the limited pool of participants that were recruited from the HIV support groups, the generalisability of the findings to HIV across different contexts might be problematic in statistical/probabilistic generalisations to a population (Popay et al. 1998).

Despite this limitation, the interpretation and analysis of these findings have a wider appeal in terms of applicability, transferability, and relevance in other contexts, beyond the Nigerian setting. In demonstrating the applicability and transferability, this research initially adopted the position of Mason (2002) who advocated the importance of scaling up of data collection ‘to produce cross-contextual understanding and explanations’ (Mason 2002: 4 as cited in Davidson et al. 2019). Scaling-up in Mason’s parlance connotes making a sample larger and more representative through longitudinal studies, which will help to recognise the value of comparing the cross-contextual data being collected at different times. When it was observed that Mason’s position fails to understand that qualitative research does not aim at generalisation but rather to provide in-depth explanations and meaning, and then apply the results to other settings through transferability (the applicability of research results and conclusion beyond the research context to other settings outside the study situation), then the transferability approach advocated by Guba and Lincoln (1989) was adopted.

However, it was further observed that the applicability of this research findings to other settings does not align with Guba and Lincoln’s transferability approach that emphasized trustworthiness, ‘fittingness’ (the degree of congruence between sending and receiving contexts), and the degree of similarity between the research setting in which the phenomenon studied occurs, and the settings to which the results are expected to be transferable (Lincoln & Guba 1985; Guba & Lincoln 1989). Guba and Lincoln’s work could be critiqued here as one-sided because the research settings do not have to be similar before transferability can ensue, and subsequently, the research findings can be applied in contexts different from the original research context, given the quality, reliability and validity of the data/findings and conclusions presented. Rather, this study’s findings align with the position of Smith (2018), which argued that transferability should not be based on the question of whether context A and context B are congruent and fit with each other, but rather focused on the extent in which research results ‘are transferable to other settings’ (Smith 2018, 140-141).

This could be undertaken by examining how previous studies especially on the practices of healthwork in other contexts align with the findings in this study.

Studies have been conducted on how elements of healthwork, especially concealment, spirituality, counselling, testing, and support group participation have been observed to be pivotal to health improvement and HIV management in Burkina Faso (Issiaka et al. 2001), Belgium (Arrey et al. 2016), Namibia (Smith & Niedermyer 2009), Uganda (Seeley et al. 2012; Mutumba et al. 2015), the United States (Polzer-Casaroz & Miles 2008; Solorzano & Glassgold 2010; Dalmida et al. 2011; Rintamaki et al. 2019), and Swaziland (Horter et al. 2019). Other contexts include Zimbabwe (Mupambireyi et al. 2014; Batenganya et al. 2015), the United Kingdom (Ridge et al. 2008), Malawi (Manzi et al. 2005), Tanzania (De Paoli et al. 2004), South Africa (Kalichman & Simbayi 2003; Visser et al. 2005; Simbayi et al. 2007; Macphail et al. 2008; Gibert & Walker 2010; Iwelunmor et al. 2010; Heyer et al. 2010; Strauss et al. 2015), and Zambia (Sanjana et al. 2009; Makworth-Young et al. 2020).

Even though these practices were studied independently in these contexts, they were not considered as a form of healthwork in the above studies. Therefore, the understanding of how one of these practices constitutes a form of healthwork to support treatment in HIV management was lacking. Despite this, some of the key results and analytical ideas in this research are applicable to understanding how these practices constitute forms of healthwork that people living with HIV utilise to respond to HIV diagnosis and manage their health in these contexts despite the variations in the experiences of HIV-positive individuals across these settings. Furthermore, the applicability of these findings can be utilised to understanding how these elements of healthwork are rooted in the biographies of HIV-positive individuals in those contexts and other settings. Therefore, these practices of healthwork are forms of strategies used by people living with HIV to reconstitute their biographies following the disruption caused by HIV diagnosis, across cultural and social contexts.

Irrespective of the limitations associated with this study, this research has further enhanced sociological knowledge on HIV management, as its findings are relevant to understanding how practices of healthwork are central to biographical reconstitution following HIV disruption; forging and deepening close interconnection between the different elements of the BBC chain; and become more encompassing than adherence in daily management of HIV. The recruitment from the support groups has helped with obtaining rich and valuable data needed to address the research questions that have been posed for this study. The data obtained from the support groups helped to develop insights that make further important contributions to the sociological knowledge, as was discussed in the previous section. In doing so, avenues for further research have also been uncovered, which are outlined below.

8.4 Suggestions for further research

The findings in this research present three avenues for further research. First, by focusing on HIV in this research, the applicability of the findings to other chronic conditions may be limited. Although practices of healthwork (dieting, adherence, testing, counselling, spirituality, and others) have been studied in separate dimensions in social studies of HIV in both Western and non-Western contexts, they are not considered as healthwork. Furthermore, these practices, which might not be considered forms of healthwork, may be performed by chronically ill patients, who are diagnosed with Alzheimer's, arthritis, asthma, cancer, and diabetes, to manage their health in everyday life. Therefore, further research could be directed to exploring whether these practices constitute forms of healthwork for people living with these chronic conditions, and the kind of healthwork that people living with HIV carry out in other countries of the world. In this sense, further cross-cultural studies in African countries and other parts of the world especially are needed to explore and compare cultural-specific experiences of those living with HIV. In fact, experiences of healthwork in other African countries would be needed, as cultural comparison would enable us to know whether the findings from this research are generalisable or transferable.

Furthermore, since social life and everyday experiences of chronic illness management are woven into the biography of people living with these chronic conditions, understanding the implications of healthwork on biographies of people with other chronic conditions is required and strongly recommended. This study offers a strong rationale for further enquiry on how biography and healthwork intersect in the experience of living with these chronic conditions.

Second, the nature of this research may warrant more longitudinal research to map out its potential impact over time. Research involving biographical issues is not static or stable over time. Therefore, further research investigating how healthwork impacts and is impacted by biography over a considerable length of time is needed. This is particularly useful in analysing and evaluating how changes in the biographical experience shape the kind of healthwork that people living with HIV undertake or perform over different temporal epochs.

The third area for further research is the gender dimension of HIV management and healthwork. The gender analysis of healthwork and HIV management would help to reveal a lot of diversity in how male and female participants understand their conditions, how HIV diagnosis affects both men and women, and how gender could shape the varying ways in which the practices of healthwork were performed by the participants. Therefore, further research on gendered differences is needed, with a view to understanding the varying degrees of experiences and responses of men and women on the impact of HIV, treatment outcome and the course of illness, biographical time, corporeality, self and identity, and reaction to stigma and discrimination. Further enquiry into the gender question would help to provide new insights into how experiences of HIV management, biography and healthwork are different between men and women, which would help to produce fresh insights into different experiential understanding of people living with HIV.

8.5 Implications for Healthcare Services

This research has further enhanced sociological knowledge of HIV management, as its findings are relevant to understanding how healthwork is integral to the personal and social fabric of HIV-positive individuals in a particular cultural context, and further contributed towards understanding the everyday experience of HIV management. This could have important implications for healthcare services and their delivery, as far as the management of chronic illness in the everyday life of chronically ill people or HIV-positive individuals is concerned. Although the research was conducted in Nigeria, the findings can help with illuminating and understanding the impacts of healthwork and its practices as biographical issues that can be woven into patient-centred care and fosters an integrated approach into the holistic understanding of health and well-being across a global context. This requires understanding healthwork and its components as biographical issues that can be woven into patient-centred care and fosters an integrated approach that incorporates patients' biography, history, personal issues, self and identity issues and structural factors, alongside clinical encounter/treatment regime into a holistic understanding of health and well-being. This would enable healthcare professionals, HIV Support organisations, and global health agencies to understand that recovery as a process is more than clinical outcomes, but rather encompasses social, cultural, and environmental factors that are coalescence around healthwork in illness context. The understanding of healthwork and its components might help healthcare professionals with new knowledge of rendering patients or ill-persons' suffering meaningful. The insights from this study might also help healthcare professionals to facilitate a holistic healthcare delivery service to clients, especially in contexts where health 'bureaucratic systems often justify exclusion of certain categories of people and therefore, cannot recognise their sufferings' (Henderson 2004, 44). The implications of this finding can be seen in the ways in which healthwork has been central to the lived experience of everyday issues that are pivotal to HIV management in the social life and biography of HIV-positive people. Therefore, the implications for healthcare services, as demonstrated by the findings in this study revealed that practices of healthwork are important tools that can help to manage illness - especially HIV - better in a clinical context.

8.6 Concluding Remarks

This research investigated the biographical implications of healthwork on the everyday lives of people living with HIV. Following Corbin and Strauss (1987), biography is defined as consisting of three main components: biographical time, the body, and the conception of self. The findings of this study have contributed to the sociological field of health and illness, by advancing our understanding of how HIV has been understood as a chronic illness, in terms of the consequences of the condition and the impact of healthwork on the biographies of HIV-positive individuals.

The practical implications of healthwork revealed that practices, such as counselling, and other components of healthwork are the aspects of HIV management or chronic illness management that are often taken for granted and are central to the biographies of the participants. Therefore, expanding healthwork to accommodate biographical issues that are disrupted by the onset of HIV will help to manage HIV more holistically in the everyday lives of people living with HIV.

Overall, this thesis illuminates the contextual factors that informed and shaped the differences in the understanding of healthwork between Western society and the Nigerian setting, and further enhanced sociological knowledge on HIV management, with respect to the understanding of how healthwork is integral to the personal and social fabric of HIV-positive individuals in a particular cultural context and further contributed towards understanding the everyday experience of HIV management. Conclusively, the findings in this study revealed how HIV management is rooted in the practices of healthwork and connected with the daily struggles and lived experiences that are central to the biographies of people living with HIV.

Bibliography

Aasbø, G., Solbraekke, K. N., Kristvik, E., & Werner, A. (2016). Between disruption and continuity: Challenges in maintaining the biographical we when caring for a partner with a severe, chronic illness. *Sociology of Health and Illness*, 38(5), 782-96.

Adam, B. D. (2011). Epistemic fault lines in biomedical and social approaches to HIV prevention. *Journal of the International AIDS Society*, 14(Suppl 2), S2-S9.

Adams, S., Pill, R., & Jones, A. (1997). Medication, chronic illness and identity: the perspective of people with asthma. *Social Science and Medicine*, 45, 189-201.

Adamsen, L., & Rasmussen, J. M., (2001). Sociological perspectives on self-help groups: Reflections on conceptualization and social processes. *Journal of Advanced Nursing*, 35(6), 909-917.

Adeiza, M. A., Abba, A. A., & Okpapi, J. U. (2014). HIV-associated tuberculosis: A sub-Saharan African perspective. *Sub-Saharan African Journal of Medicine, 1*, 1-14.

Adeokun, L., Okonkwo, P., & Ladipo, O. A. (2006). The stigmatisation of people living with HIV/AIDS. In O. Adeyi (Ed.). *AIDS in Nigeria: A Nation on the Threshold*. Cambridge, MA: Harvard University Press.

Adogame, A. (2007). HIV/AIDS Support and African Pentecostalism: The Case of the Redeemed Christian Church of God (RCCG). *Journal of Health Psychology*, 12(3), 475-484.

Agulanna, C. (2010). Community and Well-being in an African Culture. *Trames*, 14(64/59), 282-298.

Aguwa, J. (2010) Religion and HIV/AIDS prevention in Nigeria. *Crosscurrents*, 60, 208-223.

Ahmed, S., Delaney, K., Villalba-Diebold, P., Aliyu, G., Constantine N., Ememabelem, & Chamurat M. (2013). HIV counselling and testing and access-to-care needs of populations most-at-risk for HIV in Nigeria. *AIDS care*, *25*(1), 85-94.

Ajagu, N., Anetoh, M.U., & Nduka, S.O. (2017). Expanding HIV/AIDS care service sites: A cross sectional survey of community pharmacists views in South-East, Nigeria. *Journal of Pharmaceutical Policy & Practice,* 10(34), 1-12.

Akinboro, A. O., Akinyemi, S. O., Olaitan, P. B., Raji, A. A., Popoola, A. A., Awoyemi, O. R., & Ayodele, O. E. (2014). Quality of life of Nigerians living with human immunodeficiency virus. *The Pan African Medical Journal*, *18*(234). doi: 1011604/pamj.2014.18.234.2816

Akram, S. (2013). Fully unconscious and prone to habit: The characteristics of agency in the structure and agency dialectic. *Journal for the Theory of Social*

Behaviour, 43(1), 45-65.

Al-Jibaly, M. (2003). The inevitable journey part 1. *Sickness: Regulations and Exhortations* (2nd ed.). Austin, Texas: Al-Kitaab and As-Sunnah Publishing.

Alexias, G., Savvakis, M., & Stratopoulou, F. (2016). Embodiment and biographical disruption in people living with HIV/AIDS. *AIDS Care*, 28 (5), 585-590.

Alonzo, A., & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3), 303-315.

Amibor, P., & Ogunrotifa, A. B. (2012). Unravelling barriers to accessing HIV prevention services experienced by African and Caribbean communities in Canada: Lessons from Toronto. *Global Journal of Health Science*, 4(3), 1-12.

Amoran, E. (2012). Predictors of disclosure of zero-status to sexual partners among people living with HIV/AIDS in Ogun State, Nigeria. *Nigerian Journal of Clinical Practice, 15*(4), 385-390.

Andersen, R., Bozzette, S., Shapiro, M, St.clair, Morton, S., Crystal, S., Cunningham, W., S… (2000). Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the United States. *Health Services Research*, 35(2), 389-416.

Anderson R & Bury, M. *(Eds.). (*1988*). Living with chronic illness: the experience of patients and their families*. London: Unwin Hyman.

Anyan F. (2013). The influence of power shifts in data collection and analysis stages: A focus on qualitative research interview. *Qualitative Report*, 18(36), 1-9.

Archer, M.S. (1995). *Realist social theory: the morphogenetic approach.* Cambridge: Cambridge University Press.

Archer M.S. (2000). *Being human: the problem of agency*. Cambridge: Cambridge University Press.

Archer M.S. (2003). *Structure, agency, and the internal conversation.* Cambridge: Cambridge University Press.

Archer M.S. (2013). Collective reflexivity: A relational case for it. In C. Powell & De´Pelteau (Eds.). *Conceptualizing Relational Sociology: Ontological and Theoretical Issues*. (pp.) 145-61 New York: Palgrave.

Arendell, T. (1997). Reflections on the researcher-researched relationship: A woman interviewing men. *Qualitative Sociology*, 20(3), 341-368.

Argyrou, V. (2015). Cosmopolitanism, sociology and the otherness of the other. *Cultural Dynamics*, 27(3), 341-356.

Arksey, H. (1994). Expert and lay participation in the construction of medical knowledge. *Sociology of Health and Illness*, 16(4), 448-68.

Arrey, A. E., Bilsen, J., Lacor, P., & Deschepper, R. (2016). Spirituality/religiosity: A cultural and psychological resource among sub-Saharan African migrant women with HIV/AIDS in Belgium. *PLoS ONE 11*(7), e0159488.

Atkinson, J. M. (1983). *Discovering suicide: Studies in the social organisation of sudden death*. London: Macmillan Press Ltd.

Atkinson, P. (2005). Qualitative Research-Unity and diversity. *Forum: Qualitative Social Research*, 6(3), Art 26.

Atkinson, P. (2009). Illness narratives revisited: The failure of narrative reductionism. *Sociological Research Online*, 14(5), 16-22.

Attia, S., Egger, M., Müller, M. Zwahlen, M., & Low, N. (2009). Sexual transmission of HIV according to viral load and antiretroviral therapy: Systematic review and meta-analysis. *AIDS*, 23(11), 1397-404.

Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, 1, 385-405.

Auerbach J.D., & Hoppe T. A (2015). Beyond getting drugs into bodies: Social science perspectives on pre-exposure prophylaxis for HIV. *Journal of the International AIDS Society*, 18(Suppl 3), 19983.

Awofala, A. A., & Ogundele, O. E. (2018). HIV epidemiology in Nigeria. *Saudi Journal of Biological Sciences*, 25(4), 697-703.

Ayres, J.R., Paiva, V., Franca, I., Gravato, N., Lacerda, R., Negra, M.D. … Silva, M. H. (2006). Vulnerability, human rights, and comprehensive health care needs of young people living with HIV/AIDS. *American Journal of Public Health*, 96(6), 1001- 1006.

Ayuk A.E., Udonwa, N., & Gyuse, A. (2017). Influence of spirituality and religion on adherence to highly active antiretroviral therapy in adult HIV/AIDS patients in Calabar, Nigeria. *Recent Advances in Biology & Medicine,* 3, 48-57.

Babalola, S. (2007). Readiness for HIV testing among young people in Northern Nigeria: The roles of social norms and perceived stigma. *AIDS Behaviour*, 11, 759-769

Babalola, S., Fatusi, A., & Anyanti, J. (2009). Media saturation, communication exposure and HIV stigma in Nigeria. *Social Science & Medicine*, 68, 513-1520

Balfe, M. (2007). Diets and discipline: the narratives of practice of university students with type 1 diabetes. *Sociology of Health & Illness*, 29 (1), 136-153.

Balogun, A. S. (2011). Islamic perspectives on HIV/AIDS and antiretroviral treatment: The case of Nigeria. *African Journal of AIDS Research*, 9(4), 459-466.

Bangsberg, D. R., Hecht, F. M., Charlebois, E. D., Edwin, D., Zolopa, A.R., Holodniy, M., … Moss, A. (2000). Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. *AIDS*, 14, 357-366.

Bankole, O. M., & Mabekoje, O. O. (2008). Awareness and opinios about HIV/AIDS among secondary school teachers in Ogun-State, Nigeria. *Scientific Research and Essay*, *3*(6), 245-253.

Barbuto R, Biggeri M, & Griffo, G (2011). Life project, peer counselling, and self-help groups as tools to expand capabilities, agency, and human rights. *ALTER-European Journal of Disability Research*, 5(3), 137-43.

Barken, R. (2014). Caregivers' interpretations of time and biography: the experiences of caring for a spouse with Parkinson's disease. *Journal of Contemporary Ethnography*, 43(6), 695-719.

Barlow S. H., Burlingame G. M., Nebeker R. S. & Anderson, E. (2000). Meta-analysis of medical self-help groups. *International Journal of Group Psychotherapy*, 50(1), 53-69.

Barofsky, I. (1978). Compliance, adherence and the therapeutic alliance steps in the development of self-care. *Social Science and Medicine*, 12, 369-76.

Bascom, W. R. (1952). The esusu: a credit Institution of the Yoruba. *The Journal of the Royal Anthropological Institute of Great Britain and Ireland, 82* (1), 63-69.

Bashiruddin, A., (2013). Reflections on translating qualitative research data: Experiences from Pakistan. *International Journal of Applied Linguistics*, 23(3), 357-367.

Bateganya, M. H., Amanyeiwe, U., Roxo, U., & Dong, M. (2015). Impact of support groups for people living with HIV on clinical outcomes: a systematic review of the literature. *Journal of Acquired Immune Deficiency Syndromes*, *68, Suppl 3*(0 3), S368-S374.

Baumgartner, L. M. (2007). The Incorporation of the HIV/AIDS Identity into the self over time. *Qualitative Health Research*, *17*(7), 919-931.

Baumgartner, L. M. (2012). The perceived effect of the sociocultural context on HIV/AIDS identity Incorporation. *The Qualitative Report*, 17(23), 1-21.

Baumgartner, L. M., & David, K. N. (2009). Accepting being poz: the Incorporation of the HIV identity into the self. *Qualitative Health Research*, *19*(12), 1730-1743.

Baumgartner, L. M. (2007). The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research*, 17(7), 919-931.

Beck, U. (1992). *Risk society: Towards a new modernity*. London: Sage.

Bello F.A., Ogunbode O.O., Adesina O.A., & Olayemi, O. (2011). Acceptability of counselling and testing for HIV infection in women in labour at the University College Hospital, Ibadan, Nigeria. *African Health Sciences*, 11(1), 30-35.

Berkanovic, E. (1972). Lay conceptions of the sick role. *Social Forces*, 51, 53-64.

Bernays, S., Rhodes, T., & Janković-Terźić, K. (2010). You should be grateful to have medicines: Continued dependence, altering stigma and the HIV treatment experience in Serbia. *AIDS Care, 22*(sup1), 14-20.

Bharat, S. A. (2011). A systematic review of HIV/AIDS-related stigma and discrimination in India: Current understanding and future needs. *Journal of Social Aspects of HIV/AIDS, 8*(3), 138-149.

Bhasin, V. (2007). Medical anthropology: a review. *Studies on Ethno-Medicine*, 1(1), 1-20.

Biehl, J. (2007). *Will to live: AIDS therapies and the politics of survival*. Princeton, New Jersey: Princeton University Press.

Birbili M. (2000). *Translating from one language to another*. Retrieved 27 December 2018 from http://www.soc.surrey.ac.uk/sru/SRU31.html

Bletzer, K. (2007). Identity and resilience among persons with HIV: a rural African American experience. *Qualitative Health Research*, 17(2), 162-75.

Blummer, H. (1969). *Symbolic interactionism*. Englewood Cliffs, NJ: Prentice Hall.

Boeije, H., Duijnstee, S. H., & Grypdonck, M. H. (2002). Encountering the downward phase: Biographical work in people with multiple sclerosis living at home. *Social Science and Medicine*, 55(6), 881-893.

Bolton, S.C. (2015). Women's Work, Dirty Work: The gynaecology nurse as 'other'. *Gender, Work and Organization*, 12(2), 169-186.

Borkman, T. (1997). A selective look at self-help groups in the United States', *Health and Social Care in the Community*, 5, 357-364.

Borkman, T., & Munn-Giddings, C. (2008). Self-help groups challenge health care systems in the US and UK. *Advances in Medical Sociology, 10,* 127-150.

Bourdieu, P. (1977). *Outline of a theory of practice.* London: Cambridge University Press.

Boyatzis, R.E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.

Brandt, A.M. (1988). AIDS in historical perspective: Four lessons from the history of sexually transmitted diseases. *American Journal of Public Health*, 78(4), 367-371.

Brandt, R. (2008). Is it all chaos, loss and disruption? The narratives of poor, HIV-infected South African women. A centre for social science research paper. Retrieved4April,2021from file:///C:/Users/user/Downloads/Brandt_Is_it_all_chaos_2008.pdf

Brashers, D. E. Neidi, J. L., Cardillo, W. L., Dobbs, L. K., Russel, J. A., & Haas, S.M. (1999). In an important way, I did die: Uncertainty and revival in persons living with HIV or AIDS, *AIDS Care*, 11(2), 201-19.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Brenchley, J. M., Schacker, T. W., Price, D. A., Taylor, J. H., Beilman, J., Nguyen, P.L., … Douek, D. C. (2004). CD4+ T cell depletion during all stages of HIV disease occurs predominantly in the gastrointestinal tract. *Journal of Experimental Medicine*, 200, 749-75.

Broadfoot, P. & Osborn, M. (1993). *Perceptions of teaching: Primary school teachers in England and France*. London: Cassel.

Broder, S. (2010). The development of antiretroviral therapy and its impact on the HIV-1/AIDS pandemic. *Antiviral Research,* 85 (1), 1-2.

Brook I. (1987). Approval of zidovudine (AZT) for acquired immunodeficiency syndrome: a challenge to the medical and pharmaceutical communities. *Journal of American Medical Association,* 258, (11),1517.

Brooks, N. A., & Matson, R. R. (1987). Managing multiple sclerosis: In R. A. Roth, & P. Conrad (Eds.), *Research in the sociology of health care* (pp. 73-106). Greenwich: JAI.

Broom, A., Hand, K., & Tovey, P. (2009). The role of gender, environment and individual biography in shaping qualitative interview data. *International Journal of Social Research Methodology*, 12(1), 51-65.

Broom, A. (2005). Virtually healthy: the impact of internet use on disease experience and doctor-patient relationship. *Qualitative Health Research*, 15(3), 325-345.

Brouwe, D. C. (2005). Counterpublicity and corporeality in HIV/AIDS zines. *Critical Studies in Media Communication*, 22(5), 351-371.

Bryman, A. (2008). *Social research methods*. Oxford: Oxford University Press.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4*(2), 167-182.

Bury, M. R. (1988). Meaning at risk: the experience of arthritis. In K. Anderson & M. Bury (Eds.), *Living with chronic illness: the experience of patients and their families.* London: Unwin Hyman.

Bury, M. (1991). The sociology of chronic illness: a review of research and prospects, *Sociology of Health and Illness*, 13, 451-68.

Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health & Illness*, 23(3), 268-285.

Buse, C., Martin, D., & Nettleton, S. (2018). Conceptualising materialities of care: Making visible mundane material culture in health and social care contexts. *Sociology of Health and Illness*, 40, 243-55.

Cacchioni, T., & Tiefer, L. (2012). Why medicalization? Introduction to the special issue on the medicalization of sex. *Journal of Sex Research*, 49(4), 307-10.

Cáceres, C. F., Koechlin, F., Goicochea, P., Sow, P., O'Reilly, K. R., Mayer, K. H., & Godfrey-Fausett, P. (2015). The promises and challenges of pre-exposure prophylaxis as part of the emerging paradigm of combination HIV prevention. *Journal of the International AIDS Society*, 18 (Suppl 3), 19949-59.

Cáceres, C. F., O'Reilly K. R., Mayer, K. H., & Baggaley, R. (2015). PrEP implementation: Moving from trials to policy and practice. *Journal of the International AIDS Society*, 18(Suppl 3), 1-4.

Caixeta C. R., Nascimento, L. C., Pedro, I. C., & Rocha, S. M. (2012). Spiritual support for people living with HIV/AIDS: a Brazilian explorative, descriptive study. *Nursing Health Science*, 14, 514-19.

Callahan, J. (1994). The ethics of assisted suicide. *Health and Social Work*, *19*(4), 237-244.

Calcutt, L., Woodward, I., & Skrbis, Z. (2009). Conceptualising otherness: an exploration of the cosmopolitan schema. *Journal of Sociology*, 45(2), 169-186.

Camargo, K. R. (2013). Medicalization, pharmaceuticalization and health imperialism. *Cad. Saúde Pública*, 29(5), 844-846.

Carminanti, L. (2018). Generalizability in qualitative research: a tale of two traditions. *Qualitative Health Research*, 28(13), 2094-2101.

Carpenter C. J., Fischl, M. A., Hammer, S. M., Hirsch, M. S., Jacobsen, D. M., Katzenstein, D. A., … Volberding, P. A. (1996). Antiretroviral therapy for HIV infection in 1996: Recommendations of an international panel. AIDS Society-USA. *Journal of the American Medical Association,* 276(2), 146-154.

Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health and Illness,* 17, 65-88.

Cassidy, R., & Leach, M. (2009). *AIDS, citizenship and global funding: A Gambian case study.* IDS Working Paper No. 325. Brighton, UK: Institute of Development Studies (IDS).

Castillo-Mancilla, J. R., & Haberer, J. E. (2018). Adherence measurements in HIV: New advancements in pharmacologic methods and real-time monitoring. *Current HIV/AIDS Reports,* 15, 49-59.

Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health,* 95(1), 53-59.

Cataldo, F. (2008). New forms of citizenship and socio-political inclusion: Accessing antiretroviral therapy in a Rio de Janeiro favela. *Sociology of Health and Illness*, 39, 900-912.

Challacombe, L. (2011). Treatment as prevention: We have all heard about it but what does it really mean. *Canadian AIDS Treatment Information Exchange.* Retrieved January 1, 2017 from https://www.thebodypo.com

.

Chamberlain, K., Madden, K., Gabe, J., Dew, K., & Norris, P. (2011). Forms of resistance to medications within New Zealand households. *Medische Anthropologie*, 23, 299e308.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill, *Sociology of Health and Illness*, 5, 168-95.

Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. *Research in the Sociology of Health Care* 6, 283-321.

Charmaz, K. (1991). *Good days, bad days: the self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.

Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly*, 35(2), 269-88.

Charmaz, K. (1995). The body, identity and self: Adapting to impairment. *The Sociological Quarterly*, 36(4), 657-80.

Charmaz, K. (2000). Experiencing chronic illness. In G. L. Albrecht, R. Fitzpatrick and S. C. Scrimshaw (Eds.). *The handbook of social studies in health and medicine* (pp. 277-292). London: Sage Publications.

Charmaz, K. (2002a). The self as habit: the reconstruction of self in chronic illness. *The Occupational Therapy Journal of Research*, 22, 31-41.

Charmaz, K. (2002b). The self as habit: the reconstruction of self in chronic illness. *OTJR: Occupation, Participation and Health*, 22(Suppl. 1), S31-S41.

Charmaz, K. (2002c). Stories and silences: Disclosures and self in chronic illness. Qualitative Inquiry, 8, 302-328.

Charmaz, K., & Rosenfeld, D. (2006). Reflections of the body, images of self: Visibility and invisibility in chronic illness and disability. In D. Waskul and P. Vannini (Eds.). *Body/Embodiment: Symbolic interaction and the sociology of the body*. Burlington, VT: Ashgate.

Charmaz, K., & Belgrave, L. L. (2013). Modern symbolic interaction theory and health. In W. Cockerham (Ed.), *Medical Sociology on the move*. Springer: Dordrecht.

Casarez, R. L.P., & Miles, M. S. (2008). Spirituality: A cultural strength for African

American mothers with HIV. *Clinical Nursing Research, 17*(2), 118-32.

Chesney, M. A., Morin, M., & Sherr, L. (2000). Adherence to HIV combination therapy. *Social Science and Medicine*, 50, 1599-1605.

Chesney, M. A. (2003). Adherence to HAART regimens. *AIDS Patient Care and STDs*, 17, 169–177.

Chiappetta-Swanson, C. (2005). Dignity and dirty work: Nurses experiences in managing genetic termination for fetal Anomaly. *Qualitative Sociology*, 28(1), 93-116.

Ciambrone, D. (2001). Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives. *Sociology of Health and Illness*, 23(4), 517-540.

Ciambrone, D. (2003). *Women's experiences with HIV⁄AIDS: Mending fractured selves*. New York: Hayworth Press.

Clandinin, D. J., & Murphy, M. S. (2009). Relational ontological commitments in narrative research. *Educational Researcher*, 38(8), 598-602.

Clarke A., Hanson E.J. & Ross H. (2003) Seeing the person behind the patient:

enhancing the care of older people using a biographical approach. *Journal of Advanced Nursing*, 12, 697–706.

Clarke J. N., & James, S. (2003). The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science and Medicine*, 57(8), 1387-1395.

Cockerham, W. C. (1981). Medical sociology. *International Review of Modern Sociology*, 11(1), 231-250.

Coetzee, D., Hilderbrand, K., Boulle A., Maartens, G., Louis, F., Labatala, V., … Goemaere, E. (2004). Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa. *AIDS,* 18, 887-895.

Cohen, M.A., Sande, P., & Volberding, P.A. (1994). *The AIDS knowledge base*. San Francisco: University of California Press.

Cohen, J., Marcoux, I., & Bilsen, J. (2006). European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. *Social Science and Medicine, 63*, 743-756.

Cohen M., McCauley, M., & Gamble, T. R., Hosseinipour, M. C., Kumarasamy, N., Hakim, J. G., … Heming, T. R. (2011). Antiretroviral treatment to prevent the sexual transmission of HIV-1: Results from the HPTN 052 multinational randomized controlled trial. The 6th IAS Conference on HIV Pathogenesis, Treatment and Prevention, 17–20 July, Rome.

Collins, H., & Evans, R. (2002). The third wave of science studies: Studies of expertise and experience. *Social Studies of Science*, 32(2), 235-96.

Colvin, C., Robins, S., & Leavens, J. (2010). Grounding ‘responsibilisation talk’: Masculinities, citizenship and HIV in Cape Town, South Africa. *Journal of Development Studies* 46(7), 1179-1195.

Connor, E. M., Sperling, R. S., Gelber, R. Kiselev, P., Scott, G., O’Sullivan, M. J., … Balsley, J. (1994). Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Paediatric AIDS clinical trials group protocol 076 study group. *New England Journal of Medicine*, 321, 1173-1180.

Conrad, P. (1986). The social meaning of AIDS. *Social Policy*, 17, 51-56.

Conrad, P., & Barker, K. K. (2010). The social construction of Illness: Key insights and policy implications. *Journal of Health and Social Behaviour*, 51(5), 67-79.

Conrad, P. (2005). The shifting engines of medicalization. *Journal of health and social behaviour*, 46(1), 3-14.

Conrad, P. (1992). Medicalization and social control. *Annual Review of Sociology*, 18, 209-232.

Conrad, P. (1985). The meaning of medications: Another look at compliance. *Social Science and Medicine*, 20, 29-37.

Conrad, P. (1986). The social meaning of AIDS. *Social Policy*, 17. 51-56.

Conrad, P. (1987). The experience of illness: recent and new directions. In J. A. Roth and P. Conrad (Eds.), *Research in the sociology of health care: the experience and management of chronic illness*, Vol. 6. Greenwich, CT: JAI Press.

Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8, 224-247.

Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.

Corbin, J., & Strauss, A. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. *Research in the Sociology of Health Care*, 16, 249-81.

Corbin, J. (2003). The body in health and illness. *Qualitative Health Research,* 13(2), 256-267.

Coreil, J., Willke, J., & Pintado, I. (2004). Cultural Model of illness and recovery in breast cancer support groups. *Qualitative Health Research*, 14(7), 905-923.

Cornelius, L. J., Erekaha, S. C., Okundaye, J. N., & Sam-Agudu, N. A. (2018). A socio-ecological examination of treatment access, uptake and adherence issues encountered by HIV-positive women in rural north-central Nigeria. *Journal of Evidence-Informed Social Work*, 15(1), 38-51.

Cornwell, J. (1984). *Hard earned lives: Accounts of health and illness from east London*. London: Tavistock.

Coyte, P.C., & Holmes, D. (2005). Beyond the art of governmentality: Unmasking the distributional consequences of health policies. *Nursing Inquiry,13*(2), 154-160.

Crawford, R. (1994). The boundaries of the self and the unhealthy other: Reflections on health, culture and AIDS. *Social Science and Medicine,* 38(10), 1347-65.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among the five traditions*. Thousand Oaks, CA: Sage.

Cree, V. E., Kay, H., Tisdall, K., & Wallace, J. (2004). Stigma and parental HIV. *Qualitative Social Work*, 3(1), 7-25.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Crossley, M. (2001). Survivors and victims: Long-term HIV-positive individuals and the ethos of self-empowerment. *Social Science and Medicine* 45(12), 163-173.

Crossley, M. (1998). Sick role or empowerment? The ambiguities of life with an HIV-positive diagnosis. *Sociology of Health and Illness*, 20, 507-31.

Crossley, N. (1995a). Merleau-Ponty, the elusive body and carnal sociology. *Body and Society*, 1(1), 43-63.

Crossley, N. (1995b). Body, techniques, agency and intercorporeality: On Goffman's relation in public. *Sociology*, 29(1), 133-149.

Csordas, T. J. (1995). *Embodiment and experience*. Cambridge: University of Cambridge Press.

Curtis, E. B. (1961). Medication errors made by patients. *Nursing Outlook*, 9, 290.

Cushman, P. (1990). Why the self is empty: Towards a historically situated psychology. *American Psychologist*, 45(5), 599-611.

Cushman, P. (1996). *Constructing the self, constructing America: a cultural history of psychotherapy*. Cambridge, MA: Da Capo Press.

Czarniawska, B. (2004). *Narratives in social science research. Introducing qualitative methods*. London: Sage Publications.

Czapp, A. (2012). The republic of therapy: Triage and sovereignty in West Africa's time of AIDS, by Vinh-Kim Nguyen. *Anthropology and Medicine*, *19*(3), 356-359.

Dalmida, S. G., Holstad, M. M., Dilorio, C., & Laderman, G. (2012) The meaning and use of spirituality among African American women living with HIV/AIDS, *Western Journal of Nursing Research*, 34(6) 736-765.

Dalmida, S. G., Holstad, M. M., Diiorio, C., & Laderman, G. (2011). Spiritual well-being and health-related quality of life among African American women with HIV/AIDS. *Applied Research in Quality of Life*, *6*(2), 139-157.

Dahlui, M., Azahar, N., Bulgiba, A., Zaki, R., Oche, O. M., Adekunjo, F. O., & Chinna, K. (2015). HIV/AIDS related stigma and discrimination against PLWHA in Nigerian population. *PLoS ONE 10*(12), e0143749.

Damen, S., Mortelmans, D. & Van Hove, E. (2000). Self-help groups in Belgium: their place in the care network. *Sociology of Health and Illness*, 22, 331-348.

Davies, M. (1997). Shattered assumptions: Time and the experience of long-term HIV-positivity. *Social Science & Medicine*, 44, 561–571.

Davis, F. (1963). *Passage through crisis: Polio victims and their families*. Indianapolis: Bobbs-Merrill.

Davis, M. (2010). Antiretroviral treatment and HIV prevention: Perspectives from qualitative research with gay men in the UK. In M. Davis & C. Squirre (Eds.), *HIV treatment and preventive technologies in International Perspective*. Basingstoke: Palgrave Macmillan.

Davis, M., & Squire, C. (2010). *HIV technologies in international perspective* (1st ed.). London: Palgrave.

Davis, M., & Squire, C. (2010). Particularity, potentiation, citizenship and pragmatism. In M. Davis and C. Squire (Eds.), *HIV Treatment and Prevention Technologies in International Perspective*. Basingstoke: Palgrave.

Davis, M. S., & Eichhorn, R. L. (1963). Compliance with medical regimens: a panel study. *Journal of Health and Social Behaviour,* 4(4), 240-49.

Davis, M. S. (1967). Predicting non-compliant behaviour. *Journal of Health and Social Behaviour*, 8(4), 265-71.

Davis, M. S. (1968). Variations in patients' compliance with doctors' advice: an empirical analysis of patterns of communication. *American Journal of Public Health*, 58(2), 274-88.

Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, 55 (2), 205-217.

Davidson E, Edwards R, Jamieson L & Weller, S. (2019). Big data, qualitative style:

a breadth and depth method for working with large amounts of secondary qualitative data. *Quality & Quantity*, 53(1), 363-376.

Dennis, A. (2011). Symbolic Interactionism and ethnomethodology. *Symbolic Interaction*, 34(3). 349-356.

De Wet, K., & Wouters, E. (2016). Identity and the body: Narrative accounts of two HIV-positive women with lipodystrophy in post-apartheid South Africa. *Social Theory and Health,* 14 (3), 351-371.

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV Infection as a chronic disease. *Lancet*, 382 (9903), 1525-1533.

Delaney, M. (2006). History of HAART – the true story of how effective multi-drug therapy was developed for treatment of HIV disease. *Retrovirology*, 3(Suppl 1), S6.

De-Graft, A. A., Unwin, N., Agyemang, C., Allotey, P., Campbell, C., & Arhinful, D. (2010). Tackling Africa's chronic disease burden: From the local to the global. *Globalisation and Health, 6*(5). Retrieved 6 February, 2021 from https://globalizationandhealth.biomedcentral.com/articles/10.1186/1744-8603- 6-5Accessed on 10/08/2017.

Depaoli, M., Manongi, M., & Klepp, K. K. (2004). Factors influencing acceptability of voluntary counselling and HIV-testing among pregnant women in Northern Tanzania. *AIDS CARE, 16*(4), 411-42.

De´Pelteau, F. (2008). Relational thinking: a critique of co-deterministic theories of structure and agency. *Sociological Theory,* 26(1), 51-73.

De´Pelteau, F. (2013). What is the direction of the relational turn? In C. Powell and F. De´Pelteau (Eds.), *Conceptualizing relational sociology: Ontological and theoretical issues (*pp. 163-85). New York: Palgrave.

Devault, M. (1990). Talking and listening from a woman's standpoint. *Social Problems*, 37, 96-116.

De Vries, R. (1995). Towards a sociology of bioethics. *Qualitative Sociology*, 18, 119-28.

Dibb, B., & Yardley, L. (2006). How does social comparison within a self-help group influence adjustment to chronic illness? A longitudinal study. *Social Science and Medicine*, 63 (6), 1602-1613.

Donnell, D., Baeten, J. M., Kiarie, J., Thomas, K. K., Stevens, W., Cohen, C. R., … Celium, C. (2010). Heterosexual HIV-1 transmission after initiation of antiretroviral therapy: a prospective cohort analysis. *Lancet,* 375(9731), 2092-2098.

Donovan, J. L., & Blake, D. R. (1992). Patient noncompliance: Deviance or reasoned decision-making. *Social Science and Medicine*, 34(5), 507-13.

Douglas, J. D. (1967). *The social meaning of suicide*. Princeton: Princeton Legacy Library

Dunbar, J., & Stunkard, A. (1979). Adherence to diet and drug regimen. In R. Levy, B. Rifkind et al (Eds.), *Nutrition, Lipids and Coronary Heart Disease*. New York: Raven Press.

Dunbar, J. (1980). Adhering to medical advice: a review. *International Journal of Mental Health*, 9(1/2), 70-87.

Durkheim, É. (1982). *The rules of sociological method and selected texts on sociology and its method*. W. D. Halls (translator). New York: Free Press.

Dwyer, S. D., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63.

Earthy, S., & Cronin, A. (2008). Narrative analysis. In N. Gilbert (Ed.), *Researching Social Life* (3rd ed.). London: Sage.

Eck, S., & Sax, S. (2005). The ills of marginality: New perspectives on subaltern health in south Asia. *Anthropology and Medicine,* 12(3), 44-51.

Eck, S. (2005). Pharmaceutical citizenship: Antidepressant marketing and the promise of demarginalization in India. *Anthropology and Medicine* 12(3), 239-254.

Ehiri, J. E., Anyanwu, E. C., Donath, E., Kanu, I., & Jolly, P. E. (2005). AIDS-related stigma in sub- Saharan Africa: Its context and potential intervention strategies. *AIDS Public Policy Journal, 20*, 25-39.

Ehiri, J. E., Iwelunmor, J., Iheanacho, T., Blackstone, S., Obiefune, M. C.,Ogidi, A. G.,Ahunnanya, F. U., Nnadi, D., ... Ezeanolue, E. E. (2016). Using a cultural framework to understand factors influencing HIV testing in Nigeria.

International Quarterly of Community Health Education, *37*(1), 33-42. doi: 10.1177/027684X1668525.

Eisinger, R. W., Dieffenbach, C. W., & Fauci, A. S. (2019). HIV viral load and transmissibility of HIV infection: Undetectable equals untransmittable. *JAMA, 321*(5), 451-452. doi: 10:1001/jama.2018.21167.

Elliott, R. A., Ross-Degnan, D., Adams, A. S., Safran, D. G., & Soumerat, S.B. (2007). Strategies for coping in a complex world: Adherence behaviour among older adults with chronic illness. *Journal of General Internal Medicine*, 22, 805-10.

Elder-Vass, D. (2007). For emergence: Refining archers' account of social structure. *Journal for the Theory of Social Behaviour*, 37, 25-44.

Emirbayer, M., & Mishe, A. (1998). What is agency? *American Journal of Social Science*, 103(4), 962-1023.

Emlet, C. A. (2006). You're awfully old to have this disease: Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *The Gerontologist*, 46(6), 781-90.

Enger, C., Graham, N., Peng, Y., Chmiel, J. S., Kingsley, L. A., Detels, R., & Munoz, A. (1996). Survival from early, intermediate and late stage of HIV infection. *Journal of American Medical Association*, 275, 347-8.

Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology and Human Values*, 20(4), 408-37.

Evans, C., & Lewis, J. (2017). Analysing semi-structured interviews using thematic analysis: Exploring voluntary civic participation among adults. In J. Lewis (Ed.), *Sage research methods datasets.*

Exley, C. (2004). Review article: the sociology of dying, death and bereavement. *Sociology of Health and Illness*, 26(1), 110-122.

Ezzy, D., & Rice, P. (1999). *Qualitative research methods: a health focus.* Melbourne, Australia: Oxford University Press.

Ezzy, D. (2000). Illness narratives: Time, hope and HIV. *Social Science and Medicine*, 50, 605-617.

Evans, R. (2008). The sociology of expertise: the distribution of social fluency. *Sociology Compass*, 2, 281-298.

Faircloth, C. A. (2004). Energizing the ordinary: Biographical work and the future in stroke recovery narratives. *Journal of Aging Studies*, 18 (4), 399-413.

Faircloth, C. A., Rittman, M., Boylstein, C. A., Young, M., Puymbroek, M. (2004) Energizing the ordinary: Biographical work and the future in stroke recovery narratives. Journal of Aging Studies, 18(4), 399-413.

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M.E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness,* 26(2), 242-61.

Fairclough, N. (1989). *Language and power*. London: Longman.

Fatiregun, A. A., Mofolorunso, K. C., & Osagbemi, K. G. (2009). Quality of life of people living with HIV/AIDS in Kogi State, Nigeria. *Benin Journal of Postgraduate Medicine*, 11(1), 21-27.

Federal Ministry of Health. (2007). National Guidelines for HIV and AIDS treatment And Care in adolescents and adult. Retrieved November 19, 2017 from http://www.who.int/hiv/amds/Nigeria_adult_2007.pdf

Fee, E., & Fox, D. M. (1992). Introduction: the contemporary historiography of AIDS. In E. Fee and D. M. Fox (Eds.), *AIDS: the making of a chronic disease. AIDS: the making of a chronic disease.* Beckley: University of California Press.

Fee, E., & Krieger, N. (1993). Understanding AIDS: Historical interpretations and the limit of biomedical individualism. *American Journal of Public Health*, 83(10), 1477-86.

Feinberg, M. B. (1996). Changing the natural history of HIV disease. *Lancet*, 348, 239-46.

Felde, L. H. (2011). Elevated cholesterol as biographical work – Expanding the concept of biographical disruption. *Qualitative Sociology Review*, 7(2), 101-120.

Feldman, D. A. (1994). *Global AIDS Policy*. Westport CT: Bergin and Garvey.

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods,* 5(1), 80-92.

Ferlie, E., McGivern, G., & FitzGerald, L. (2012). A new mode of organizing in health care: Governmentality and managed networks in cancer services in England. *Social Science and Medicine, 74*(3), 340-347.

Fink, A. S. (2000). The role of the researcher in qualitative research process: a potential barrier to archiving qualitative data. *FORUM: Qualitative Social Research*, 1(3), Art 4.

Fischl, M. A., Richman, D. D., Grieco, M. H., Gottlieb, M. S.,Volberding, P. A., Laskin, O. L., … Schooley, R.T. (1987). The efficacy of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex. A double-blind, placebo-controlled trial. *New England Journal of Medicine*, 317, 185-191.

Fischl, M. A., Olson, R. M., Follansbee, S.E., Lalezari, J. P., Henry, D. H., Frame, P. T., … Soo, W. (1993). Zalcitabine compared with zidovudine in patients with advanced HIV-1 infection who received previous zidovudine therapy. *Annual Internal Medicine*, 118, 321-330.

Fitzpatrick, R. D., Brew B. K., & Perkins, D. (2021). A sociological autopsy lens on older adult suicide in rural Australia: Addressing health, psychosocial factors and care practices at the intersection of policies and institutions. *Social Science and Medicine, 284*, 1-9.

Flick, U. (2009). *An Introduction to qualitative research* (4th ed.). London, Sage.

Flowers, P., Davis M., Hart, G., Rosengarten, M., Frankis, J., & Imrie, J. (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*, 21(1), 109-122.

Flowers, P. (2010). HIV transitions: Consequences for self in an era of medicalisation. In M. Davis, & C. Squire (Eds.), *HIV treatment and prevention technologies in international perspective*. London: Palgrave Macmillan.

Folasire, O. F., Irabor, A. E., & Folasire, A. M. (2012). Quality of life of people living with HIV and AIDS attending the antiretroviral clinic, University College Hospital, Ibadan, Nigeria. *African Journal of Primary Education Sector, 4(*1), 1-12.

Fontana, A., & Frey, J. H. (2000). The Interview: From structured questions to negotiated texts. *Handbook of Qualitative Research*, 2, 645-72.

Foucault, M. (1973). *Madness and civilisation*. London: Random House.

Foucault, M. (1974). *The birth of the clinic*. London: Random House.

Foucault, M. (1977). *Discipline and punish*. London: Penguin.

Foucault, M. (1986). The use of pleasure. In *The history of sexuality*, Vol. 2. Harmondsworth: Viking.

Foucault, M. (1988). Technologies of the self. In L. Martin, H. Gutman, & P. Hutton (Eds.), *Technologies of the self: A seminar with Michel Foucault*. Amherst: The University of Massachusetts Press, pp. 16-49.

Foucault, M. (2007). *Security, territory, population lectures at the College of France.*1977e78. New York: Picador.

Francis, L. J., Breskaya, O., & McKenna, U. (2020). Attitudes toward civil human rights among Italian students of sociology: The effects of religion and theology. *Religions, 11*(643), 1-20.

Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago: Chicago University Press.

Frank, E. (2006). Negotiating futures in the time of AIDS: Inheritance disputes among the Tonga in Southern Province, Zambia (Doctoral dissertation, University of Indiana, Bloomington).

Frank, E. (2009). The relation of HIV testing and treatment to identity formation in Zambia. *African Journal of AIDS Research, 8*(4), 515-524.

Frankenberg, R. (1980). Medical anthropology and development: a theoretical perspective. *Social Science and Medicine*, 14B, 197-207.

Freedom House. (2017). *Internet freedom in Nigeria.* Freedom on the net publication. Retrieved January 2, 2019 from https://freedomhouse.org/report/freedom-net/2017/nigeria.

Freeman, E. (2016). Neither foolish nor finished: Identity control among older adults with HIV in rural Malawi. *Sociology of Health and Illness*, 27(6), 835-848.

Frith, H., & Gleeson, K. (2004). Clothing and embodiment: Men managing body image and appearance. *Psychology of Men and Masculinity*, 5, 40-48.

Frye, V., Fortin, P., & MacKenzie, S. (2009). Managing identity impacts associated with disclosure of HIV status: a qualitative investigation. *AIDS Care*, 21(8), 1071- 1078.

Gabb, J. (2011). Family lives and relational living: Taking account of otherness. *Sociological Research Online*, 16(4), 10.

Gabe, J., Bury, M., & Elston, M. A. (Eds.). (2004). *Key concepts in medical sociology*. London: Sage Publications.

Gagnon, M., & Holmes, D. (2012). Women living with HIV/AIDS and the bodily transformation process known as lipodystrophy: a grounded theory study. *Journal of Research in Nursing*, 17(3), 215-228.

Gagnon, M., & Holmes, D. (2010). Women living with HIV/AIDS and the bodily transformation process known as the lipodystrophy syndrome: a grounded theory study, *Journal of Research in Nursing*, 0(0), 1-14.

Gagnon, M., & Holmes, D. (2011). Bodies in mutation: Understanding lipodystrophy among women living with HIV/AIDS. *Research and Theory for Nursing Practice: An International Journal*, 25(1), 23-38.

Gagnon, M., & Holmes, D. (2016). Body-drug assemblages: Theorizing the experience of side effects in the context of HIV treatment. *Nursing Philosophy*, *17*(4), 250–261.

Gallagher, E. B. (1976). Lines of reconstruction and extension in Parsonsian sociology of illness. *Social Science and Medicine*, 10: 207-18.

Ganga, D., & Scott, S. (2006). Cultural "Insiders" and the Issue of positionality in qualitative migration research: Moving "across" and moving "along" researcher-participant divides**.** *Forum Qualitative Sozialforschung/ Forum: Qualitative Social Research*, 7(3), Art 7.

Geertz, C. (1980). Blurred genres: the refiguration of social thought. *American Scholar*, 49, 165-179.

Genberg, B. L., Hlavka, Z., Konda, K. A., Maman, S., Chariyalertsak, S., Chingono, A., ... Celentano, D. D. (2009). A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. *Social Science and Medicine*, *68*, 2279-2287.

George, L. K., Larson, D. B., Koenig, H. G., & McCullough, M. E. (2000). Spirituality and health: What we know, what we need to know. *Journal of Social and Clinical Psychology*, 19(1), 102-116.

Gerhardt, U. (1990). Introductory essay: Qualitative research in chronic illness. The issue and the story. *Social Science and Medicine, 30*, 1149 -59.

Gerhardt, U. (1979*a*). The Parsonsian paradigm and the identity of medical sociology. *Sociological Review*, 27(2), 229-51.

Gerson, E. M. (1976). The social character of illness: Deviance or politics. *Social Science and Medicine*, 10, 219-24.

Gibbs, J. P., & Martin, W. T. (1968). On status integration and suicide (I). *Social Problems*, 15(4), 510-512.

Giddens, A. (1979). *Central problems in social theory: Action, structure and contradiction in social analysis*. Basingstoke: Macmillan.

Giddens, A. (1984). *The constitution of society: Outline of the theory of structuration*. Cambridge: Polity Press.

Gilbert, L., & Walker, L. (2010). ‘My biggest fear was that people would reject me once they knew my status…’: Stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health and Social Care in the Community, 18*(3): 325-335.

Gilroy, P. (1991). *There ain't no black in the Union Jack: the cultural politics of race and nation.* Chicago: University of Chicago Press.

Gimlin, D. (2007). What is body work? A review of the literature. *Sociology Compass,* 1(1), 353-70.

Given, L. M. (2008). *The SAGE encyclopaedia of qualitative research methods*. Thousand Oaks, CA: SAGE Publications, Inc.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. London: Weidenfeld and Nicholson.

Glaser, B., & Strauss, A. (1965). *Awareness of dying*. Chicago: Aldine.

Glaser, B., & Strauss, A. (1968). *Time for dying*. Chicago: Aldine.

Glaser, B.G. (2005). The impact of symbolic interaction on grounded theory. *Grounded Theory Review*, 4(2),1-22.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.

Gostin, L. O., & Webber, D. (1998). The AIDS litigation project: HIV/AIDS in the courts in the 1990s, part 2. *AIDS and Public Policy Journal*, *13*, 3-19.

Goudge, J., Manderson, L., & Ngoma, B., & Schneider, H. (2009). Stigma, identity and resistance among people living with HIV in South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 6*(3), 94-104.

Gray R.E., Fitch M. et al. (1996). Breast cancer and prostate cancer self-help groups: Reflections on differences. *Psycho-Oncology*, 5, 137-142.

Gray R.E., Fitch M. et al. (1997) Interviews with men with prostate cancer about their self-help group experience. *Journal of Palliative Care*, 13, 15-21.

Greeff, M., Phetlhu, R., Makoae, L. N., Dlamini, P. S., Holzemer, W. L., Naidoo, J. R., Kohi, T. W., Uys, L. R., & Chirwa, M. L. (2008). Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qual Health Res., 18*(3), 311-324. doi: 10:1177/1049732307311118. PMID:18235155.

Green, G., & Sobo, E.J. (2000). The endangered self: Managing the social risks of HIV. Routledge: London.

Greenbank, P. (2003). The role of values in educational research: the case of reflexivity. *British Educational Research Journal*, 29(6), 7.

Grmek, M.D. (1990). *History of AIDS: Emergence and origin of modern pandemic*. New Jersey: Princeton University Press.

Grundmann, R. (2017). The problem of expertise in knowledge societies. *Minerva*, *55* (1), 25-48.

Guba, E. G. & Lincoln Y. S. (1989). *Fourth generation evaluation*. Sage: Newbury Park.

Gurevich, M. (1996). *Identity renegotiation in HIV-positive women*. Dissertation abstracts international, 58(07), 3967B.

Gurevitch, Z. D. (1988). The other side of dialogue: On making the other strange and the experience of otherness. *American Journal of Sociology*, 93(5), 1179-99.

Hackett, R. I. (1988). The Academic Study of Religion in Nigeria. *Religion*, 18(1), 37-46.

Hall, S. (1997). *Representation: Cultural representations and signifying practices*. Milton Keynes: Sage Publications.

Hallas, R. (2009). *Reframing bodies: AIDS, bearing witness, and the queer moving image.* Durham, NC, Duke University Press.

Hamberg, K., & Johansson, E. (1999). Practitioner, researcher, and gender conflict in a qualitative study. *Qualitative Health Research*, 9, 455-467.

Hammer, S. M., Katzenstein, D. A., & Hughes, M. D., Gundacker, H., Schooley, R., Haubrich, R. H., … Mengan, T. C. (1996). A trial comparing nucleoside monotherapy with combination therapy in HIV-infected adults with CD4 cell counts from 200 to 500 per cubic millimetre. AIDS Clinical Trials Group 175 Study Team, (pp. 1081-1090 *New England Journal of Medicine*, 335.

Häkli, J. (2009). Governmentality. *International Encyclopedia of Human Geography, 4*: 628-633.

Halman, L., & van Ingen, E. (2015). Secularization and changing moral views: European trends in church attendance and views on homosexuality, divorce, abortion, and euthanasia, *European Sociological Review*, *31*(5), 616-627.

Halverson, S. L. (1997). The concept of equivalence in translation studies: Much ado about something. *Target: International Journal of Translation Studies*, *9*(2), 207-233.

Hardey, M. (1999). Doctor in the house: the internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health and Illness*, 21, 6, 1545-53.

Harnett, T., & Jönson, H. (2017). They are different now – Biographical continuity and disruption in nursing home settings. *Journal of Aging Studies*, 42, 1-8.

Haug, N.A. (2006). HAART adherence strategies for methadone clients who are HIV-positive. *Behaviour Modification*, 30(6), 752-781.

Hayes, N. (1997). Theory-led thematic analysis: Gocial identification in small companies. In N. Hayes (Ed.), *Doing qualitative analysis in psychology*. East Sussex: Psychology Press.

Hazell, C. (2003). *The experience of emptiness*. Bloomington, IN: Author House

Health Reform Foundation of Nigeria. (2007). *Impact, challenges and long-term implications of antiretroviral therapy programme in Nigeria.* Retrieved from www.herfon.org/docs/HERFON_ART_Report.pdf on February 5, 2013.

Healy, K. (1998). Conceptualising constraint: Mouzelis, Archer and the concept of social structure. *Sociology*, 32(3), 509-522.

Hecht, F.M., Colfax, G., Swanson, M., & Chesney, M.A. (1998). Adherence and effectiveness of protease inhibitors in clinical practice. *Fifth Conference on Retroviruses and Opportunistic Infections*. Chicago, Illinois.

Hecht, S.S. (2002). Cigarette smoking and lung cancer: Chemical mechanisms and approaches to prevention. *The Lancet Oncology*, 3(8), 461- 469.

Henderson, P.C. (2004). vertiginous body and social metamorphosis in a context of HIV/AIDS, *Anthropology Southern Africa*, 27, (1-2), 43 - 53.

Hesse, M., Forstmeier, S., Mochamat, M., & Radbruch, L. (2019). A Review of

Biographical Work in Palliative Care. *Indian journal of palliative care*, *25*(3), 445–454.

Herek, G.M., & Glunt, E.K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist*, 43(11), 886-891.

Herek, G. M., Capitanio, J. P., & Widanman, K. F. (2003). Stigma, social risk, and health policy: Public attitudes towards HIV surveillance policies and the social construction of illness. *Health Psychology, 22*(5), 533-540.

Herzlich.C., & Pierret, J. (1987). *Illness and self in society.* Baltimore: The Johns Hopkins University Press.

Heyer, A. S., Mabuza, L. H., Couper, I. D., & Ogunbanjo, G. A. (2008). Understanding participation in a hospital-based HIV support group in Limpopo Province, South Africa. *SA Fam. Pract., 52*(3), 234-239.

Hirsch, J. (2007). Gender, sexuality, and antiretroviral therapy: Using social science to enhance outcomes and inform secondary prevention strategies. *AIDS*, *21*(Suppl. 5), S21eS29.

Hodes, R., Cluver, L., Toska, E., & Vale, B. (2020). Pesky metrics: the challenges of measuring ART adherence among HIV-positive adolescents in South Africa. *Critical Public Health*, 30,2, 179-190.

Holmes, D. (2002). Nursing as means of governmentality. *Journal of advanced nursing, 38*(6), 557-565.

Horn, R. (1997). Not one of the boys: Women researching the police. *Journal of*

Gender Studies, 6, 297- 308.

Horne, R., Weinman, J., Barber, N., & Elliot, R. (2002). Concordance, adherence and compliance in medicine taking. London: National Co-ordinating Centre for NHS Service Delivery and Organisation.

Horter, S., Bernays, S., Thabede, Z., Dlamini, V., Kerschberger, B., Wringe, A (2019) “I don’t want them to know”: How stigma creates dilemmas for engagement with treat-all HIV care for people living with HIV in Eswatini. *African Journal of AIDS Research, 18*(1), 27-37. doi: 10.2989/16085906.2018.1552163.

Howarth, G., & Jefferys, M. (1996). Euthanasia: Sociological perspectives. *British Medical Bulletin, 52*(2), 376-385.

Howson, A., & Inglis, D. (2001). The body in sociology: Tensions inside and outside sociological thought. *The Sociological Review*, 49(3), 298-317.

Huddy, L., Billig, J., Bracciodieta, J., Hoeffler, L., Moynihan, P. J., & Puglian, P. (1997). The effect of Interviewer gender on the survey response. *Political Behaviour*, 19 (3), 197-220.

Hunt, L. M., Jordan, B., Irwin, S., Browner, C. H. (1989). Compliance and the patient's perspective: Controlling symptoms in everyday life. *Culture, Medicine and Psychiatry*, 13, 315-334.

Hydén, L. C. (1997). Illness and narrative. *Sociology of Health and Illness,19*(1), 48-69.

Ibrahim, J. (1991). Religion and political turbulence in Nigeria. *Journal of Modern African Studies*, 29 (1), 115-136.

Idigbe, E. O., Adewole, T. A., Eisen, G., Kanki, P., Odunukwe, N. N., Onwujekwe, D.I., … Adesola, Z. M. (2005). Management of HIV-1 infection with a combination of nevirapine, stavudine, and lamivudine: a preliminary report on the Nigerian antiretroviral program. *Journal of Acquire Immune Deficiency Syndrome*, 40(1), 65-69.

Idoko, J. A., Akinsete L., Abalaka, A. D., & Keshinro, B. (2002). A multicentre study to determine the efficacy and tolerability of a combination of nelfinavir, zalcitabine and zidovudine. *West African Journal of Medicine*, 21(2), 83-86.

Igun, U. A. (1988). *Medical sociology: An introduction*. Shaneson: C. I. Press.

Isaksen, L. W. (2002). Masculine dignity and the dirty body. *Nora: Nordic Journal of Women's Studies*, 10(3), 137-146.

Issiaka, S., Cartoux, M., Ky-Zerbo, O., Tiendrebeogo, S., Meda, N., Dabis, F., & Van de Perre, P. (2001). Living with HIV: Women's experience in Burkina Faso, West Africa. *AIDS Care, 13*(1), 123-8.

Isiugo-Abanihe, U. C. (1994). Extramarital relations and perceptions of HIV/AIDS in Nigeria, *Health Transition Review,* 4, 111-125.

Islami, F., Torre, L. A., &Jemal, A. (2015). Global trends of lung cancer mortality and smoking prevalence. *Translational Lung Cancer Research*, *4*(4), 327-338.

Iwelunmor, J., Zungu, N., & Airhihenbuwa, C. O. (2010). Rethinking HIV/AID disclosure among women within the context of motherhood in South Africa. *American Journal of Public Health*, *100*(8), 1393-1399.

Izugbara, C.O., & Wekesa, E. (2011). Beliefs and practices about antiretroviral medication: a study of poor urban Kenyans living with HIV/AIDS. *Sociology of Health & Illness*, 33(6), 869-883.

James, A., & Hockey, J. (2007). *Embodying health identities*. Basingstoke, Palgrave Macmillan.

Jappah, J. V. (2013). The convergence of American and Nigerian religious conservatism in a biopolitical shaping of Nigeria's HIV/AIDS prevention programmes. *Global Public Health*, 8(3), 312-325.

Jobling, R. (1988). The experience of psoriasis under treatment. In R. Anderson *and M.* Bury (Eds.), *Living with chrome illness: the experience of patients and their families.* London: Unwin Hyman.

Joffe, H. (1999). *Risk and the other*. Cambridge: Cambridge University Press.

Jowsey, T. (2016). Time and chronic illness: a narrative review. *Quality of Life Research*, 1-10.

Joyce, R. A. (2005). Archaeology of the body. *Annual Review of Anthropology*, 34(1), 139-158.

Joyce, P. (2001). Governmentality and risk: Setting priorities in the new NHS. *Sociology of Health and Illness, 23*(5), 594-614.

Jurick, N.C. (1987). Persuasion in a self-help group: Processes and consequences. *Small Group Behavior*,18, 368-397.

Jurriaans, S. (1994). The natural history of HIV-1 infection: Virus load and virus phenotype independent determinants of clinical course? *Virology*, 204(1), 223-233.

Jutel, A. (2015). Beyond the Sociology of Diagnosis. *Sociology Compass*, 9(9), 841-52.

Jupp, P. C. (2016). *Contemporary issues in the sociology of death, dying and disposal*. New York: Springers.

Kadiri, K. K., Ahmad, M. K., & Mustaffa, C. S. (2014). HIV/AIDS and cultural practices in Nigeria: An implication for HIV/AIDS preventive communication campaign. *New Media and Mass Communication*, 27, 19-30.

Kalichman, S. C., & Simbayi, L. C. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*, *79*(6), 442-447.

Kaplan, J. E., Masur, H., Jaffe, H. W., & Holmes, K. K. (1995). Reducing the impact of opportunistic infections in patients with HIV Infection: New Guidelines. *Journal of American Medical Association*, *274*(4), 347-348.

Karp, D. (1992). Illness ambiguity and the search for meaning: A case study of a self-help group for affective disorders. *Journal of Contemporary Ethnography*, 21(2), 139-50.

Kawuma, R., Bernays, S., Siu, G., Rhodes, T., & Seeley, G. (2014). Children will always be children: Exploring perceptions and experiences of HIV-positive children who may not take their treatment and why they may not tell. *African Journal of AIDS Research*, 13(2), 185-195.

Keating, J., Meekers, D., & Adewuyi, A. (2006). Assessing effects of a media campaign on HIV/AIDS awareness and prevention in Nigeria: Results from the VISION Project. *BMC Public Health*, 6(123), 1-12.

Kelly, J. S., Langdon, D., & Serpell, L. (2009). The phenomenology of body image in men living with HIV/AIDS*. Care*, 21(12), 1560-1567.

Kelly, M., & Dickson, H. (1997). The narrative self in the autobiographical accounts of illness. *The Sociological Review*, 45 (2), 254-74.

Kelly, M. (1991). Coping with an ileostomy. *Social Science and Medicine*, 33, 115-125.

Kelly, M. (1992). Self, identity and radical surgery. *Sociology of Health and Illness*, 14, 390-415.

Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health and Illness*, 18, 241-257.

Kelley, M. & Eberstadt, N. (2005). *Behind the veil of a public health crisis: HIV/AIDS in the Muslim World*. Washington, D.C.: National Bureau of Asian Research.

Keogh, P. (2017). Embodied, clinical and pharmaceutical uncertainty: people with HIV anticipate the feasibility of HIV treatment as prevention (TasP). *Critical Public Health*, 27(1), 63-74.

Kieffer, T. L., Finucane M. M., Nettles, R. E., Quinn, T.C., Broman, K. W., Ray,S.C. Persaud, D., … & Siliciano, R. F. (2004). Genotypic analysis of HIV-1 drug resistance at the limit of detection: Virus production without evolution in treated adults with undetectable HIV loads. *The Journal of Infectious Diseases*, 189 (8), 1452-1465.

King, A. (1999). Against structure: a critique of morphogenetic social theory. Sociological Review, 42(7), 199-227.

King, R., Katuntu D, Lifshay, J., Parkel, L., Batamwita, R., Nakayiwa, S., … Bunnel, R. (2008). Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behaviour*, 12, 232- 243.

Kippax, S., & Stephenson, N. (2012). Beyond the distinction: Between biomedical and social dimensions of HIV. Prevention through the lens of a social public health. *American Journal of Public Health*, 102(5), 789-799.

Kippax, S., & Stephenson, N. (2016). *Socializing the biomedical turn in HIV prevention*. London: Anthem Press.

Khalil, R. M., Nggada, H. A., Harry, T. O., & Anjorin, C. O. (2004). Manifestations of aggressive atypical Kaposi's Sarcoma (AAKS) in HIV disease patients seen in Maidguri, north-eastern Nigeria. *African Journal of Clinical and Experimental Microbiology, 5*(1), 14-45.

Kharsany, A. B., & Karim, Q. A. (2016). HIV Infection and AIDS in sub-saharan Africa: Current status, challenges and opportunities. *The open AIDS journal*, *10*, 34-8

Kremer, H., Ironson G., & Kaplan, L. (2009). The fork in the road: HIV as a potential positive turning point and the role of spirituality. *AIDS Care*, 21, 368-77.

Kuteesa, M., Seeley, J., Cumming, R., & Negin, J. (2012). Older people living with HIV in Uganda: Understanding their experience and needs. *African Journal of AIDS Research*, 11, 4, 295-305.

Kuriansky, J. (2016). *The psychosocial aspects of a deadly epidemic: What Ebola has taught us about holistic healing*. California: Praeger.

Kvale, S. (1996). *Interviews: an introduction to qualitative research Interviewing*. Thousand Oaks: Sage.

Labov, W. (1997). Some further steps in narrative analysis. *Journal of Narrative and Life History,* 7, 395-415.

Langdon, E. J. & Wiik, F. B. (2010). Anthropology, health and illness: An introduction to the concept of culture applied to the health sciences. *Rev. Latino-Am. Enfermagem*,*18*(3), 459-66.

Langford, S. E., Ananworanich J., & Cooper, D. A. (2007). Predictors of disease progression in HIV infection: a review. *AIDS Research and Therapy,* 4 (11), 1-14.

Larson, M. L. (1991). *Translation: theory and practice, tension and interdependence*. Binghamton, NY: State University of New York.

Larson, J. S. (1996). The World Health Organization's definition of health: Social versus spiritual health. *Social Indicator Research, 38*(2), 181-192.

Larson, M. L. (1998) *Meaning-based translation: A guide to cross-language equivalence* (2nd ed.). New York: University Press of America.

Lawn S. D., Myer, L, Orrell C., Bekker, L., & Wood, R. (2005). Early mortality among adults accessing a community-based antiretroviral service in South Africa: Implications for programme design. *AIDS*, 19, 2141-2148.

Lawton, J. (1998). Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. *Sociology of Health and Illness*, 20 (2), 121-143.

Lawton, J. (2003). Lay experiences of health and illness: Past research and future agendas. *Sociology of Health and Illness*, 25(3), 23-40.

LeBel, T. B. (2008). Perceptions of and response to stigma. *Sociology Compass*, 2(2), 409-432.

Lekas, H., M., Siegel, K., Leider, J. (2011). Felt and enacted stigma among HIV/HCV-

coinfected adults: the impact of stigma layering. *Qualitative Health Research*, 21(9), 1205-1219.

Leong, J., Molassiotis, A., Marsh, H. (2004). Adherence to health recommendations after a cardiac rehabilitation programme in post-myocardial infarction patients: the role of health beliefs, locus of control and psychological status*. Clinical Effectiveness in Nursing*, 8(1), 26-38.

Leusenkamp, A. (2010). Religion, authority and their interplay in the shaping of antiretroviral treatment in western Uganda. *African Journal of AIDS Research,* 9(4), 419-427.

Lester, D., & Abe, K. (1998). The suicide rate by each method in Japan: A test of Durkheim's theory of suicide. *Archives of Suicide Research, 4*(3), 281-285.

Letamo, G. *(2004).* HIV/AIDS-related stigma and discrimination among adolescents in Botswana. *African Population Studies, 19*(2), 191-204*.*

Levy, J. M., & Storeng, K.T. (2007). Living positively: Narrative strategies of women

living with HIV in Cape Town, South Africa. *Anthropology and Medicine*, 14(1), 55-68.

Lieberman, M. A., & Videka-Sherman, L. (1986). The impact of self-help groups on the mental health of widows and widowers. *American Journal of Orthopsychiatry*, 56, 435-449.

Liamputtong, P., Haritavorn, N., & Kiatying-Angsulee, N. (2009). HIV and AIDS,

stigma, and AIDS support groups: Perspectives from women living with HIV and AIDS in central Thailand. *Social Science and Medicine*, 69 (6), 862-868.

Lincoln, Y. S., and Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lindsay, S. (2009). Prioritizing Illness: Lessons in self-managing multiple chronic diseases. *Canadian Journal of Sociology*, 34(4), 983-1002.

Locock, L., Dumelow, C., & Ziebland, S. (2009). Biographical disruption, abruption and repair in the context of motor neurone disease. *Sociology of Health and Illness*, 31(7), 1043 -1058.

Locock L., Ziébland, S. (2015). Mike Bury: Biographical disruption and long-term and other health conditions. In F. Collyer (Ed.), *The Palgrave handbook of social theory in health*, *illness and medicine*. London: Palgrave Macmillan.

Lohman, D., Schleifer, R., & Amon, J. J. (2010). Access to pain treatment as a human right. *BMC Med*, 8(8): 1-9.

Lubkin, I. M., & Larsen, P. D. (2006). *Chronic illness: Impact and interventions.* Burlington, MA: Jones & Bartlett Learning.

Lundgren, J. D., Phillips, A. N., Pedersen C., Clumeck, N., Gatell, J. M., Johnson, A.

M., … Nielsen, J.O. (1994). Comparison of long-term prognosis of patients with AIDS treated and not treated with zidovudine. AIDS in Europe Study Group, *Journal of American Medical Association,* 271, 1088-1092.

Lupton, D. (2012). M-Health and health promotion: the digital cyborg and surveillance society, *Social Theory & Health*, 10(3), 229-44.

Lupton, D. (1996). The feminine 'AIDS body' in television drama: People with

HIV/AIDS on television. *Media International Australia*, 80, 99-109.

Lutfey, K., (2005). On practices of 'good doctoring': reconsidering the relationship between provider roles and patient adherence. (pp. 421- 447 Sociology of Health and Illness, 27(4).

Mackworth-Young, C. R. S., Bond, V., & Wringe, A. (2020). Secrets and silence: Agency of young women managing HIV disclosure. *Medical Anthropology, 39*(8), 720-734.

MacPhail, C. L., Pettifor, A., Coates, T., & Rees, H. (2008). 'You must do the test to know your status': Attitudes to HIV voluntary counseling and testing for adolescents among South African youth and parents. *Health Education and Behavior*, 35(1), 87-104.

Manzi, M., Zachariah, R., Teck, R., Buhendwa, L., Kazima, J., Bakali, E., Firmenich, P., & Humblet, P. (2005). High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: Scaling-up requires a different way of acting. *Trop Med Int Health, 10*(12), 1242-50.

Margolis, D. A., Gonzalez-Garcia, J., Stellbrink, H. J., Eron, J. J., Yazdanpanah. Y., Podzamczer, D., … Spreen, W. R. (2017). Long-acting intramuscular cabotegravir and rilpivirine in adults with HIV-1 infection (LATTE-2): 96-week results of a randomised, open-label, phase 2b, non-inferiority trial. *Lancet*, 390(10101), 1499-1510.

Marsland, R. (2012). (Bio)Sociality and HIV in Tanzania: Finding a living to support a life. *Medical Anthropology Quarterly, 26,* 470-485.

Marshall, M., & Rossman, G.B. (1999). *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage.

Martin, J. C., & Hitchcock, M. J., De Clerq, E., & Prussof, W. H. (2009). Early

nucleoside reverse transcriptase inhibitors for the treatment of HIV: a brief history of stavudine (D4T) and its comparison with other dideoxynucleosides. *Antiviral Research,* 85(1), 34-38.

Martin, C. M., & Peterson, C. (2009). The social construction of chronicity: A key to understanding chronic care transformations. *Journal of Evaluation in Clinical Practice, 15*(3), 578-585.

Martin, G. P., & Waring, J. (2018). Realising governmentality: Pastoral power, governmental discourse and the (re)constitution of subjectivities. *The Sociological Review*, 66(6),1292-1308.

Mason, J. (1996). *Qualitative Researching*. Thousand Oaks, CA: Sage.

Mason, J. (2002). *Qualitative researching* (2nd ed.). London: Sage.

Mason, J. (2002). Qualitative research resources: A discussion paper. Swindon, UK: ESRC

Matoti-Mvalo, T., & Puoane, T. (2011). Perceptions of body size and its association with HIV/AIDS. *South African Journal of Clinical Nutrition*, 24,1-6.

Mattes, D. (2012). I am also a human being! Antiretroviral treatment in local moral worlds. *Anthropology and Medicine*, 19(1), 75-84.

Mattes, D. (2011). 'We are just supposed to be quiet': The production of adherence to antiretroviral treatment in urban Tanzania. *Medical Anthropology, 30*, 158-182.

May, T. (1999). Reflexivity and sociological practice. (pp. 184-192) *Sociological Research Online,* 4(3).

Mayer, K., & Venkatesh K. (2010). Antiretroviral therapy as HIV prevention. *American Journal of Public Health*, 100(10), 1867-1876.

Maynard, E. S. (1996). The Translocation of a West African banking System: The Yoruba esusu rotating credit association in the Anglophone Carribean. *Dialectical,* 21(1), 99-107.

Mazanderani, F., & Paparini, S., (2015). 'The stories we tell': Qualitative research interviews, talking technologies and the 'normalisation' of life with HIV. *Social Science & Medicine, 131*, 66-73.

McCoy, L. (2009). Time, self and the medication day: a closer look at the everyday work of adherence. *Sociology of Health and Illness*, 31(1), 128-146.

Mead, G. M. (1934). *Mind, self and society*. Chicago: The University of Chicago Press.

Meloni, S. T., Chang, C. A., & Eisen, G., Jolayemi, T., Banigbe, B., Okonkwo, P. I., & Kanki, P. J. (2016). Long-term outcomes on antiretroviral therapy in a large scale-up program in Nigeria. *PLoS ONE*, 11(10), e0164030.

Merleau-Ponty, M. (1962). *Phenomenology of Perception.* London: Routledge and Kegan Paul.

Mervis, Z. (2012). The role played by NGOs in augmenting government efforts towards the achievement of Millennium Development Goal of Combating HIV and AIDS in Zimbabwe. *Journal of Public Administration and Governance*, 2(4), 95-109.

Mfecane, S. (2011). Negotiating therapeutic citizenship and notions of masculinity in a South African Village. *African Journal of AIDS Research, 10*, 129-138.

Miedema, F. (1992). Immunological abnormalities in the natural history of HIV infection: mechanisms and clinical relevance. *Immunodeficiency Reviews*, 3(3), 173-193.

Miller, A. N., & Rubin, D. L. (2007). Factors leading to self-disclosure of positive HIV diagnosis in Nairobi, Kenya: People living with HIV/AIDS in the Sub-Sahara. 586-598) *Qualitative Health Research*,17, 586-598.

Mills. (1959). *The Sociological Imagination*, Harmondsworth: Penguin.

Minocha, A. A., Mishra, A., & Minocha, V. R. (2011). Euthanasia: A social science perspective. *Economic and Political Weekly, 46*(49), 25-28.

Mischler, E.G. (1986). *Researching interview: Context and narrative*. Cambridge, MA*:* Harvard University Press.

Molinari, V., Nelson, N., Shekelle, S., & Crothers, M. K. (1994). Family support groups of the Alzheimer's Association: an analysis of attendees and non-attendees. *Journal of Applied Gerontology*, 13 (1), 86-98.

Molzahn, A., Sheilds, L., Bruce, A. et al. (2012) People living with serious illness: stories of spirituality. *Journal of Clinical Nursing,* 21, 2347-57.

Mokoae, L. N., Greeff, M., Phetlhu, R. D., Uys, L. R., Naidoo, J. R., Kohi, T. W., ... Holzemer, W. L. (2008). Coping with HIV-related stigma in five African countries. *Journal of the Association of Nurses in AIDSCare,19(*2), 137-146.

Monaghan, L. (1999). Challenging medicine? Body building, drugs and risk. *Sociology of Health and Illness*, 21(6), 707-734.

Monjok, E., Smesny, A., & Essien, E. J. (2009). HIV/AIDS-related stigma and discrimination in Nigeria: Review of research studies and future directions for prevention strategies. *African Journal of Reproductive Health*, 13(3), 21-35.

Monjok, K., Smesny, A, Okokon, I. B., Mgbere, O., & Essien, E. J. (2010). Adherence to antiretroviral therapy in Nigeria: an overview of research studies and Implication for policy and practice. *HIV/AIDS-Research and Palliative Care*, 2, 69-76.

Montagnier, L. (2002). A history of HIV discovery. *Science*, 298, 17-27.

Montaner, J. S., Reiss, P., & Cooper, D., Vella, S., Harris, M., Conway, B., Lange, J. M. (1998). A randomized, double-blind trial comparing combinations of nevirapine, didanosine, and zidovudine for HIV-infected patients. The INCAS Trial; Italy, the Netherlands, Canada and Australia Study. *JAMA*, 279, 930-937.

Montaner, J. (2011). Treatment as prevention – a double hat-trick. *The Lancet*, 378 (9787), 208-9.

Montez, J. K., & Karner, T. X. (2005). Understanding the diabetic body-self. *Qualitative Health Research*, *15*(8), 1086-1104.

Moss, A. R., & Bacchetti, P. (1989) Natural history of HIV infection. *AIDS*, 3(2), 55-62.

Moulton, B. E., Hill, T. D. & Burdette, A. (2006). Religion and trends in euthanasia attitudes among U.S. Adults, 1977-2004. *Sociological Forum 21*(2), 249-272.

Mouzelis, N. (1989). Restructuring structuration theory. *Sociological Review*, 37(4), 613-635.

Mouzelis, N. (2000). The subjectivist-objectivist divide: Against transcendence. *Social Science*, 34(4), 741-762.

Muoghalu, C.O. (2018). Factors influencing adherence to anti-retroviral therapy among people living with HIV/AIDS attending the state hospital, Osogbo, Nigeria. *HIV and AIDS Review*, 17(4), 288-298.

Mugumbate, J., & Nyanguru, A. (2013) Exploring African Philosophy: The value of Ubuntu in social work. *African Journal of Social Work*, 3(1): 82-100.

Mulubale, S. (2019). Identity, governmentality and development: A study of Zambian teachers living with and affected by HIV and therapeutic citizenship. (Doctoral dissertation, University of East London). Accessible at https://repository.uel.ac.uk/download/db0401f55610de01180c8eb7d8c8d47a500f396cf16f419d06e18ccfdd13e376/4655004/2019_PhD_Mulubale.pdf

Mulubale, S. (2020a). Therapeutic citizenship and the teaching profession: New theoretical approaches of Zambian teachers living with human immuno-deficiency virus (HIV) and on antiretroviral therapy (ART). *Malcolm Moffat Multidisciplinary Journal of Research and Education*, 1(1), 1-34.

Mulubale, S. (2020b). Understanding the seriousness of ‘self’ identity and changing process of HIV among Zambian school teachers living with antiretroviral therapy (ART). *Athens Journal of Health and Medical Sciences, 7*(4), 197-216.

Mulubale, S., Mundando, J., Munkoyo, D. N., & Ilubala-Ziwa, J. L. (2020). School teachers’ health and ‘therapeutic citizenship’ in Zambia: Problems and prospects. *Journal of Education and Practice*, 11(36), 147-156.

Mupambireyi, Z., Bernays, S., Bwakura-Dangarembizi, M., & Cowan, F. M. (2014). ‘I don't feel shy because I will be among others who are just like me…’: The role of support groups for children perinatally infected with HIV in Zimbabwe. *Children and Youth Services Review*, *45*, 106-113.

Murdoch, J., Salter, C., Cross, J., Smith, J., & Poland, F. (2013). Resisting medications: Moral discourses and performances in illness narratives. *Sociology of Health and Illness,* 35, 449-464.

Murphy, E., & Dingwall, R. (2001).The ethics of ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Loftland, & L. H. Loftland (Eds.), *Handbook of ethnography*, London: Sage.

Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology*, 5, 337-347.

Muschert, G. W. (2006). Self-affirmation through death: A contribution to the sociology of suicide through literature. *Sociological Inquiry, 76*(3), 297-315.

Mutalemwa, P., Kisoka, W., Nyigo, V., Barongo, V.,Malecela, M.N., & Kisinza, W.N. (2008). Manifestations and reduction strategies of stigma and discrimination on people living with HIV/AIDS in Tanzania. *Tanzanian Journal of Health Research,10*(4), 220-225.

Mutumba, M., Bauermeister, J. A., Musiime, V., Byaruhanga, J., Francis, K., Snow R. C., & Tsai, A. C. (2015). Psychosocial challenges and strategies for coping with HIV among adolescents in Uganda: A qualitative study. *AIDS Patient Care STDS, 29*(2), 86-94.

Mutch, A. (2004). Constraints on the internal conversation: Margaret Archer and the structural shaping of thought. *Journal for the Theory of Social Behaviour,* 34(4), 429-445.

Mvo, Z., Dick, J., & Steyn, K. (1999). Perceptions of overweight African women about acceptable body size of women and children. *Curationis*, 22(2), 27-31.

Mwaanga, O., & Banda, D. (2014). A postcolonial approach to understanding sport-based empowerment of people living with HIV/AIDS (PLWHA) in Zambia: The case of the cultural philosophy of Ubuntu. *Journal of Disability and Religion*, 18(2), 173-191.

Mykhalovskiy, E. (2008). Beyond decision Making: Class, community organizations, and the healthwork of people living with HIV/AIDS. Contributions from institutional ethnographic research. *Medical Anthropology*, 27(2), 136-163.

Mykhalovskiy, E., McCoy, L., & Bresalier, M. (2004). Compliance/adherence, HIV, and the critique of medical power. *Social Theory and Health*, 2, 315-340.

Mykhalovskiy, E., & McCoy L. (2002). Troubling ruling discourses of health: using institutional ethnography in community-based research. *Critical Public Health*, 12, 17-37.

Mykhalovskiy, E. (2010). Integrating HIV treatment and prevention: Shifts in community-based organising and biopolitics in the Canadian context. *In* M. Davis and C. Squire (Eds.), *HIV treatment and prevention technologies in international perspective*, (pp. 61-86). Basingstoke, UK: Palgrave Macmillan.

Naidu, T., Sliep, Y., & Dageid, W. (2012). The social construction of identity in HIV/AIDS home-based care volunteers in rural KwaZulu-Natal, South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 9*(2), 113-126.

Nambiar, D. (2012). HIV-related stigma and NGO-isation in India: a historico-empirical analysis. *Sociology of Health and Illness,* 34(5), 714-729.

National Agency for the Control of Aids. 2009). *HIV/AIDS: National strategic framework for action (2005 to 2009).* Abuja: NACA.

National Agency for the Control of Aids. (2010). *National HIV/AIDS strategic plan (2010-2015*). Abuja: NACA.

National Agency for the Control of Aids. (2015a). *Global AIDS response country progress report* (Nigeria GARPR 2015). Retrieved 5 April, 2021 from NACA website: https://www.unaids.org/sites/default/files/country/documents/NGA_narrative_report_2015.pdf

National Agency for the Control of Aids. (2015). HIV prevalence rate in Nigeria. Retrieved September 30, 2017, from https://naca.gov.ng/nigeria-prevalence-rate/.

National Agency for the Control of Aids. (2015b). *National HIV strategy for adolescents and young people, 2016-2020*. Retrieved 5 April, 2021 from NACA website: http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_532857.pdf.

National Agency for the Control of Aids. (2017). National strategic framework on HIV and AIDS: 2017-2021. Retrieved 5 April, 2021 from NACA website: https://www.childrenandaids.org/sites/default/files/2017-11/NATIONAL-HIV-AND-AIDS-STRATEGIC-FRAMEWORK.pdf.

National Agency for the Control of Aids. (2017). Nigeria's HIV prevalence rate. Retrieved September 25, 2017, from https://naca.gov.ng/nigeria-prevalence-rate/

Narasimha, B. C., Anand, P., Ravish, K. S., Navya, S. S., & Ranganath, T. S. (2017). Role of self-help groups in women empowerment and health. *International Journal of Community Medicine and Public Health*, 3(8), 2026-2028.

Nettleton, S., & Watson, J. (1998). *The body in everyday life*. London: Routledge.

Nettleton, S. (2004). The emergence of e-scaped medicine. *Sociology*, 38(4), 661-679.

Nettleton, S. (2013). *Sociology of health and illness* (3rd ed.*).* Cambridge: Polity Press.

Nettleton, S., Burrows, R., & O'Malley, L. (2005). The mundane realities of the everyday lay use of the internet for health, and their consequences for media convergence, *Sociology of Health and Illness*, 27(7), 972-992.

Nguyen, V., Bajos, N., Dubois-Arber, F., O'Malley, J., & Pirkle, C. M. (2011). Remedicalizing an epidemic: From HIV treatment as prevention to HIV treatment is prevention. *AIDS*, 25 (3), 291-293.

Nguyen, V. (2009). Government-by-exception: Enrolment and experimentality in mass HIV treatment programmes in Africa. *Social Theory and Health*, 7, 196-217.

Nguyen, V. K. (2005). Antiretroviral globalism, biopolitics and therapeutic citizenship. In A. Ong & S. J. Collier (Eds.), *Global assemblages: Technology, politics and ethics as anthropological problems* (pp. 124-144). Oxford, UK: Blackwell.

Nguyen, V. K. (2010).*The republic of therapy: Triage and sovereignty in West Africa's time of AIDS.* Raleigh, NC: Duke University Press.

Nguyen, V. K., Ako, C. Y., Niamba, P., Sylla, A., & Tiendrébégo, I. (2007). Adherence as therapeutic citizenship: Impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS, 21*(Suppl. 5), S31-S35.

Nieuwkerk, P.T., Gisolf, E. H., Van Leeuwen, R., Danner, S. A., DeBoer, J. B., Chesney, M. A., & Sprangers, M. A. (1998). *Self-reported adherence to ritonavir/saquinavir and ritonavir/saquinavir/stavudine in a randomized clinical : Preliminary results*. In Abstract 32362, 12th World AIDS Conference, Geneva, 28 June-3 July.

Nokes, K. M. (1991). Applying the chronic illness Trajectory Model to HIV/AIDS, *Scholarly Inquiry for Nursing Practice*, 5(3), 197-204.

Norris, P., Chamberlain, K., Dew, K., Gabe,J., Hodgetts, D., & Madden, H. (2013). Public beliefs about antibiotics, infection and resistance: A qualitative study. *Antibiotics*, 2(4), 465-476.

Nwagwu, W.E. (2008) Effectiveness of sources of HIV/AIDS awareness in a rural community in Imo State, Nigeria. *Health Information Library Journal*, 25(1), 38-45.

Nyblade, L.C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health and Medicine*, 11(3), 335-345.

Nyblade, L., & MacQuarrie, K. (2006). *Can we measure HIV/AIDS-stigma and discrimination? Current knowledge about quantifying stigma in developing countries.* ICRW: The Policy Project.

Oakley, A. (1981). Interviewing women: a contradiction in terms. In H. Roberts (Ed.), *Doing feminist research* (pp. 31- 61). London: Routledge and Kegan Paul.

Oakley, A. (1998). Gender, methodology and people's ways of knowing: Some problems with feminism and the paradigm debate in social science. *Sociology*, 32(4), 707-731.

Oakley, A. (1999). People's way of knowing: Gender and methodology. In S. Hood, B. Mayall & S. Oliver (Eds.). *Critical issues in social research*. Buckingham: Open University Press.

Obi, C. (2009). *Globalisation and access to HIV/AIDS drugs*. CODESTRIA Research and policy briefs. Retrieved from http://www.nai.uu.se/CyrilObiAIDSDrugs.pdf

Obiagwu, P. N., Hassan-Hanga, F., & Ibrahim, M. (2013). Pediatric HIV in Kano, Nigeria. Nigerian *Journal of Colonial Practice, 16*(4), 22-38.

Odafe, S., Torpey, K., Khamofu, H., Ogbanufe, O., Edward, O. A., Kuti, O., … Chabikuli, O. (2012). The pattern of Attrition from an antiretroviral treatment program in Nigeria. *PLoS ONE,* 7(12), 1-7.

Odimegwu, C. O., Akinyemi, J. O., & Alabi, O. O. (2017). HIV-stigma in Nigeria: Review of research studies, policies, and programmes. *AIDS Research and Treatment,* Article 5812650. doi: 10.1155/2017/5812650.

Odutolu, O., Ahonsi, B. A., Gboun, M., & Jolayemi, O. M. (2006). The national response to HIV/AIDS. In O. Adeyi (Ed.), *AIDS in Nigeria: a nation on the threshold* (pp. 248-252). Cambridge, MA: Harvard University Press.

Ogunrotifa, A. B (2020). Expanding marginalisation in pharmaceutical citizenship: A case study of an antiretroviral therapy user. *International Journal of Applied Sociology, 10*(1), 13-24.

Ogunrotifa, A. B. (2021). At the helm of HAART: The experience of biographical time among people living with HIV in Nigeria. *Social Sciences and Humanities Open, 3*(1), 1-9.

Olaore, I. B., & Olaore, A. Y. (2014). Is HIV/AIDS a consequence or divine judgment? Implications for faith-based social services. A Nigerian faith-based university study. *Journal of Social Aspects of HIV/AIDS, 11*(1), 20-25.

Olley, B. O., Ogunde, M. J., Oso, P. O., & Ishola, A. (2016). HIV-related stigma and self-disclosure: The mediating and moderating role of anticipated discrimination among people living with HIV/AIDS in Akure, Nigeria. *AIDS Care, 28*(6), 726-730.

Oluduro, O. (2010). The role of religious leaders in curbing the spread of HIV/AIDS in Nigeria. *Potchefstroom Electronic Law Journal, 13*(3), 208-236.

Ojenike, J. O., & Olowoniyi, A. O. (2013). Estimating growth in investment of micro and small-scale enterprises in Nigeria. *Asian Economic and Financial Review*, 3(1), 111-123.

Okareh, O. T., Akpa, O. M., Okunlola, J. O., & Okoror, T. A. (2015). Management of conflicts arising from disclosure of HIV status among married women in southwest Nigeria. *Health Care for Women International*, 36(2), 149-160.

Okoli, C. I., & Cleary, S. M. (2011). Socioeconomic status and barriers to the use of free antiretroviral treatment for HIV/AIDS in Enugu State, south-eastern Nigeria, *African Journal of AIDS Research*, 10(2), 149-155.

Okoli, C., Van de Velde, N., Richman, B., Allan, B., Castellanos, E., Young, B., Brough, G., Eremin, A., … de Los Rios, P. (2021). Undetectable equals untransmittable (U = U): Awareness and associations with health outcomes among people living with HIV in 25 countries. *Sexually Transmitted Infections, 97(1)*, 18-26.

Okoronkwo, I., Okeke, U., Chinweuba, A., & Iheanacho, P. (2013). Non-adherence factors and sociodemographic characteristics of HIV-Infected adults receiving antiretroviral therapy in Nnamdi Azikiwe University Teaching Hospital, Nnewi, Nigeria. *ISRN AIDS*, 1-8.

Okoror, T. A., Airhihenbuwa, C. O., Zungu, M., Makofani, D., Brown, D. C., & Iwelunmor, J. (2007). 'My mother told me I must not cook anymore' – Food, culture, and the context of HIV and AIDS-related stigma in three communities in South Africa. *Int Q Community Health Educ, 28*(3), 201-213.

Oku, A.O., Eme, T., Owoaje, E.T., & Oku, O.O (2014). Prevalence and determinants of adherence to highly active antiretroviral therapy amongst people living with HIV/AIDS in a rural setting in south-south Nigeria. *African Journal of Reproductive Health*, 18(1), 133-144.

Okunola, O. A., Muoghalu, C.O., & Irinoye, A. I. (2018). Socio-cultural factors influencing adherence to antiretroviral therapy among people living with HIV/AIDS in Obafemi Awolowo University Teaching Hospital, Ile-Ife, Nigeria*.* *ARC Journal of AIDS*, 3(1), 1-14.

Okoror, T. A., Falade, O. O., Olorunlana, A., Walker, E. M., & Okareh, E. M. (2013). Exploring the cultural context of HIV stigma on antiretroviral therapy adherence among people living with HIV/AIDS in southwest Nigeria. *AIDS Patients Care and STDs*, 27(1), 55-64.

Oleribe, O. O., Oladipo, O., Osita-Oleribe, P., Nwachukwu, C., Nkwopara, F., Ekom, E., Nsubuga, P. (2014). Commonization of HIV/AIDS services in Nigeria: the need, the processes, and the prospects. *The Pan African Medical Journal*, 19 (329), 1-8.

Oliffe, J., & Mroz, L. (2005). Men interviewing men about health and illness: Ten lessons learned. *Journal of Men's Health and Gender*, 2, 257-260.

Oloyede, J. A. (2008). Informal financial sector, savings mobilization and rural development in Nigeria: Further evidence from Ekiti State of Nigeria. *African Economic and Business Review*, 6(1), 35-63.

Onifade, A. A., Ajeigbe, K. O., Omotosho, I.O., Rahamon, S. K., & Oladeinde, B. H. (2013). Attitude of HIV patients to herbal remedy for HIV infection in Nigeria. *Nigerian Journal of Physiological Science*, 28, 109-112.

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. *Forum: Qualitative Social Research*, 7, Article 11. Retrieved August 28, 2018 from http://www.qualitative-research.net/fqs-texte/4-06/06-4-11- e.htm.

Orona, C. (1990). Temporality and identity loss due to Alzheimer's disease. *Social Science and Medicine*, 30 (11), 1247-1256.

Orubuloye, I. O., & Oguntimehin, F. (1999) Death is pre-ordained, it will come when it is due: Attitudes of men to death in the presence of AIDS in Nigeria. *Resistance to Behavioural change to reduce HIV/AIDS infection*, 5,101-111.

Onyebuchi-Iwudibia, O., & Brown, A. (2014). HIV and depression in eastern Nigeria: The role of HIV-related stigma. *AIDS Care, 26*(5), 653-657.

Overing, J. (1987). Translation as a creative process: The power of the name. In L. Holy (Ed.), *Comparative Anthropology*. Oxford: Basil Blackwell.

Overstreet, N. M., Earnshaw, V. A., Kalichman, S. C., & Quinn, D. M. (2013). Internalized stigma and HIV status disclosure among HIV-positive black men who have sex with men. *AIDS Care*, *25*(4), 466-471.

Palmer, S. (1989). AIDS as metaphor. *Society*, 26, 45-51.

Palmisano, L., & Vella, S. (2011). A brief history of antiretroviral therapy of HIV infection: success and challenges. *Ann 1st Super Sanita*, 47(1), 44-48.

Paudel, V., & Baral, K.P (2015). Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial and the role of support groups as a coping strategy: review of literature. *Reproductive Health,* 12, 53.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine,* 57(1), 13-24.

Parker, R., Bajanja, E., Karamagi, E., & Tindyebwa, D. (2007). AIDS-related stigma: Perceptions of family caregivers and health volunteers in western Uganda. *World Health and Population*, 9(2), 5-13.

Parsons, S. K., Cruise, P.L., & Davenport, W. M., & Jones, W. M. (2006). Religious beliefs, practices and treatment adherence among individuals with HIV in the southern United States. *AIDS Patient Care and STDS*, 20(2), 97-111.

Parsons, T. (1951). *The Social system*. London: Routledge & Kegan Paul.

Patterson, A. S. (2016). Engaging therapeutic citizenship and clientship: Untangling the reasons for therapeutic pacifism among people living with HIV in urban Zambia. *Global Public Health*, 11(9), 1121-1134.

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, California: Sage Publications.

Pearce, C. (2008). World Interrupted: an autoethnographic exploration into the rupture of self and family narratives following the onset of chronic illness and death of another. *Qualitative Sociology Review*, 4(1), 131-149.

Persson, A., Race, K., & Wakeford, E. (2003). HIV health in context: Negotiating medical technology and lived experience. *Health*, 7(4), 397-415.

Persson, A. (2005). Facing HIV: Body shape change and the (in)visibility of Illness. *Medical Anthropology*, *24*(3), 237-264.

Persson, A. (2013). Non-infectious corporealities: Tensions in the biomedical era of

HIV normalisation. (pp. 1065-1079) *Sociology of Health and Illness*, 35(7), 1065- 1079.

Persson, A. (2011). Non/Infectious bodies: a qualitative analysis of HIV corporeality in the wake of the Swiss consensus statement. *Culture, Health and Sexuality*, 9(12), 145-165.

Persson, A., Newman, C. E., Mao, L., & De Wit, J. (2016). On the margins of

pharmaceutical citizenship: Not taking HIV medication in the "treatment revolution" era. *Medical Anthropology Quarterly*, 30, 359-377.

Persson, A. (2004). Incorporating pharmakon: HIV, medicine, and body shape change. *Body and Society*, 10(4), 45-67.

Persson, A. (2005). Facing HIV: Body shape change and the (in)visibility of illness, *Medical Anthropology*, 24(3), 237-264.

Persson, A. (2010). Reflections on the Swiss Consensus Statement in the context of qualitative interviews with heterosexuals living with HIV. *AIDS Care*, 22 (12), 1487-92.

Petersoo, P. (2007). Reconsidering otherness: Constructing Estonian identity. *Nations*

and Nationalism, 13(1), 117-133.

Petrakaki, D., Hilberg, E., & Waring, J. (2018) Between empowerment and self-discipline: Governing patients' conduct through technological self-care. *Social Science and Medicine*, 213 ,146-153. hair, J. (1994). Variations in the natural

history of HIV Infection. *AIDS Research & Human Retroviruses*, 10(8), 451-59.

Petryna, A. (2002). *Life exposed: Biological citizens after Chernobyl*. Princeton, NJ: Princeton University Press.

Petryna, A., & Kleinman, A. (2006). Pharmaceutical Nexus. In A. Petryna, A. Lakoff, & A. Kleinman, (Eds.), *Global pharmaceuticals: Ethics, markets, and practices*. Durham, NC: Duke University Press.

Pierret, J., 1992. Coping with AIDS in everyday life. In M. Pollak, G. Paicheler, J.

Pierret (Eds.), *AIDS: A Problem for Sociological Research*. London: Sage.

Pierret, J. (2000). Everyday life with AIDS/HIV: Surveys in the social sciences. *Social*

Science and Medicine, 50, 1589-1598.

Pierret, J. (2001). Interviews and biographical time: The case of HIV long-term non-progressors. *Sociology of Health and Illness*, 23(2), 157-177.

Pierret, J. (2003). The illness experience: State of knowledge and perspectives for research. *Sociology of Health and Illness*, 25, 4-22.

Pierret, J. (2007). An analysis over time (1990-2000) of the experiences of living with HIV. *Social Science and Medicine*, 65 (8), 1595-1605.

Pini, B. (2005). Interviewing Men: Gender and the collection and interpretation of qualitative data. *Journal of Sociology*, 41(2), 201-216.

Pocius, J. (2016). Of Bodies, borders, and barebacking: the geocorpographies of HIV. In H. Randell-Moon & T. Ryan (Eds.), *Security, race, biopower: Essays on technology and corporeality*. London: Palgrave Macmillan.

Podzamczer, D., Ferrer, E., & Consiglio, E.,Gatell, J. M., Perez, P., Perez, J. L.,…

Estella, J. (2002). A randomized clinical trial comparing nelfinavir or nevirapine associated to ZDV/3TC in HIV- infected naïve patients (The Combine Study). *Antiviral Therapy*, 7, 81-90.

Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the

systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8(3), 341-351.

Pope, W. (1975). Concepts and explanatory structure in Durkheim's theory of suicide. *British Journal of Sociology, 26*(4), 417-434.

Pope, C., & May, N. (Eds.). (2008). *Qualitative research in health care*. Oxford: John Wiley and Sons.

Pound, P., Britten, N., Morgan, M., Yardly, L., Pope, C., DAker-White, G., &

Campbells, R. (2005). Resisting medicines: a synthesis of qualitative studies of medicine. *Social Science and Medicine*, 61(1), 133-55.

Pound, P., Gompertz, P., & Ebrahim, S. (1998). Illness in the context of older age: the case of stroke. *Sociology of Health and Illness*, 20 (4), 489-506.

Prevention Access Campaign. (2016). U=U Consensus Statement.

Prince, R., Kearns, R., & Craig, D. (2006). Governmentality, discourse and space in the New Zealand health care system1991–2003. *Health and Place, 12*(3), 253-266.

Prior, L. (2003). Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health and Illness*, 25, 41-57.

Puoane, T., & Hughes, G. (2005). Impact of the HIV/AIDS pandemic on non-communicable disease prevention. *SAMJ, 95*(4), 228-230.

Punch, K. F. (1998). *Introduction to social research: Quantitative and qualitative approaches*. Thousand Oaks: Sage.

Radley, A. (1989). Style, discourse and constraint in adjustment to chronic illness. *Sociology of Health and Illness*, 11, 230-52.

Raj, S. M. (2008). Public awareness and sensitization campaigns on HIV/AIDS in Nigeria. *The Journal of Pan African Studies*, 2(4), 215-24.

Reeve, J., Lloyd-Williams, M., Payne, S., & Dowrick, C. (2010). Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health*, 14, 178-195.

Reich, A., & Turnbull, M. (2018). Using Foucault: Genealogy, governmentality and the problem of chronic illness. *Genealogy, 2*(13), 1-12.

Reicher, S. & Hopkins, N. (2001). *Self and nation: categorisation, contestation and mobilisation*. London: Sage.

Reis, C., Heisler, M., Amowitz, L. L., Moreland, R. S., Mafeni, J. O., Anyamelo, C., Iacopino, V. (2005). Discriminatory attitudes and practices by health workers toward patients with HIV/AIDS in Nigeria. *PLoS Medicine*, 2(8), e246.

Richards, L. (2005). *Handling qualitative data: a practical guide.* London: Sage.

Richardson, A., & Goodman, M. (1983). *Self-help and social care: Mutual aid organisations in practice*. London: Policy Studies Institute.

Richardson, J. C., Ong, B. N., & Sim, J. (2008). Experiencing and controlling time in everyday life with chronic widespread pain: a qualitative study. *BMC Musculoskeletal Disorders*, 9 (3), 1-8.

Richards, N. (2017). Old age rational suicide. *Sociology Compass, 11*(3), e12456. doi: 10.1111/soc4.12456

Richards, N., & Rotter, R. (2013). Desperately seeking certainty? The case of asylum applicants and people planning an assisted suicide in Switzerland. *Sociological Research Online, 18*(4), 26.

Ridge, D., Williams, I., Anderson, J., Elford, J. (2008). Like a prayer: The role of spirituality and religion for people living with HIV in the UK. *Sociology of Health and Illness, 30*(3), 413-28.

Riessman, C. H. (1987). When gender is not enough: Women interviewing women. *Gender and Society*, 1(2), 172-207.

Riessman, C. K. (2008). *Narrative methods for the human sciences.* London: Sage.

Riessman, C. H. (1990). Strategic uses of narrative in the presentation of self and illness: a research note. *Social Science and Medicine*, 30(11), 1195-2000.

Riessman, C. H. (1993). *Narrative analysis*. Newbury Park: Sage.

Riessman, C. H. (2008) *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage Publications.

Rintamaki, L., Kosenko, K., Hogan, T., Scott, A. M., Dobmeier, C., Tingue, E., & Peek, D. (2019). The role of stigma management in HIV treatment adherence.

International Journal of Environmental Research and Public Health, *16*(24), 5003.

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice*. London, Sage.

Rittman, M., Faircloth, C., Boylstein, C., Gubrium, J. F., Williams, C., Puymbroeck, M. V., & Ellis, C. (2004). The experience of time in the transition from hospital to home following stroke. *Journal of Rehabilitation Research and Development*, 41, 259–268.

Rhine, K. A. (2015). ‘She lives dangerously’: Intimate ethics, grammatical personhood, and HIV/AIDS in Islamic northern Nigeria. *Africa Today, 61*(4), 85-103.

Rhodes, T., Harris, M., & Martin, A. (2013). Negotiating access to medical treatment and the making of patient citizenship: The case of hepatitis C treatment. *Sociology of Health and Illness,35,* 1023-1044.

Roberts, B. (2002). *Biographical research*. Buckingham: Open University Press.

Robins, S. (2005). From ‘medical miracles’ to normalised medicine: AIDS treatment, activism and citizenship in the UK and South Africa. *Working paper series, 252*. Brighton: Institute of Development Studies (IDS).

Robins, S. (2008). *From revolution to rights in South Africa: Social movements, NGOs and popular politics after apartheid*. Woodbridge, Suffolk; Rochester, NY: Boydell & Brewer. Retrieved June 13, 2021, from http://www.jstor,prg/stable/107722/j.ctt1bh2mg3

Robins, S., & von Lieres, B. (2004). Remaking citizenship, unmaking marginalization: The treatment action campaign in post-apartheid South Africa. *Canadian Journal of African Studies, 38*(3), 575-586.

Robins, S., & von Lieres, B. (2009). AIDS activism and globalisation from below: Occupying new spaces of citizenship in post-apartheid South Africa. *IDS Bulletin*, *35*(2), 84-90.

Robinson, I. (1988) *Multiple sclerosis*. London: Routledge.

Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine*, 30(11), 1173-1186.

Rodger, A. J., Cambiano, V., Bruun, T., Vernazza, P., Collins, S., Degen, O., ... Lundgren, J. (2019). Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV- positive partner taking suppressive antiretroviral therapy (PARTNER): Final results of a multicentre, prospective, observational study. *Lancet, 393*(10189), 2428-2438.

Rohleder, P., & Gibson, K. (2006). We are not fresh: HIV-positive women talk of their experience of living with their ‘Spoiled Identity.’ *South African Journal of Psychology, 36*(1), 25-44.

Root, R. (2009). Religious participation and HIV-disclosure rationales among people living with HIV/AIDS in rural Swaziland. *African Journal of AIDS Research*, 8(3), 295-309.

Rose, N., & Novas, C. (2005). Biological citizenship. In A. Ong & S. J. Collier (Eds.), *Global assemblages: Technology, politics and ethics as anthropological problems*, pp. 439-463. Malden, MA: Blackwell Publishers.

Rosengarten, M., & Michael, M. (2009). The performative function of expectations in translating treatment to prevention: the case of HIV pre-exposure prophylaxis, or PrEP. *Social Science and Medicine*, 69, 1049-1055.

Rosengarten, M. (2009). *HIV Interventions: Biomedicine and the traffic between information and flesh*. Seattle, WA: University of Washington Press.

Rosengarten, M., Imrie, P. F., Davis, M. D., & Hart, G. (2004). After the euphoria: HIV medical technologies from the perspective of their prescribers. *Sociology of Health and Illness*, 26, 575-596.

Rosenthal-Fischer, W. (2002). Biographical work and biographical structing in present-day societies. London: Routledge.

Roth, J. (1963). *Timetables*. New York: Bobbs-Merrill.

Roth, N. L., & Nelson, M. S. (1997). HIV diagnosis rituals and Identity narratives. *AIDS Care*, 9(2), 161-79.

Royce, R. A., Luckmann, R. S., Fusaro, R., & Winkelstein, W. (1991). The natural history of HIV-1 infection: Staging classifications of disease. *AIDS, 5*(4), 355-364.

Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., Wilson, M., … Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: A series of meta-analyses. *BMJ Open*, 6(7), e011453.

Russell, S, Zalwango F, Namukwaya S., Katongole, J., Muhumuza, R., Nalugya, R., … Seeley, J. (2015). *Antiretroviral therapy and changing patterns of HIV stigmatisation in Entebbe, Uganda. Sociology of Health and Illness*, *38* (1), 58-72.

Russell, S., Namukwaya, S., Zalwango, F., & Seeley, J. (2016). The framing and fashioning of therapeutic citizenship among people living with HIV taking antiretroviral therapy in Uganda. *Qualitative Health Research, 26*(11),1447-58.

Russell, S., & Seeley, J. (2010). The transition to living with HIV as a chronic condition: Working to create order and control on anti-retroviral therapy. *Social Science and Medicine*, 70, 375-82.

Ryen, A. (2004). Ethical issues. In C. Seale, G. Gobo, and J. F. Gubrium (Eds.), *Qualitative research practice*. London: Sage.

Sabaté E. (2003). *Adherence to long-term therapies: Evidence for action*. Geneva, Switzerland: World Health Organization.

Saddiq, A., Tolhurst, R., Lalloo, D., & Theobald, S. (2010). Promoting vulnerability or resilience to HIV? A qualitative study on polygamy in Maiduguri, Nigeria. *AIDS Care, 22*(2), 146-151.

Sampson, E. (1993). *Celebrating the other: a dialogic account of human nature*. London: Harvester Wheatsheaf.

Sanderson, T., Calnan, M., Morris, M., Richards, P., & Hewlett S. (2011). Shifting normalities: Interactions of changing conceptions of a normal life and the normalization of symptoms in rheumatoid arthritis. *Sociology of Health and Illness*, 33, 618-633.

Sandstrom, K. L. (1990). Confronting deadly disease: the drama of identity construction among gay men with AIDS. *Journal of Contemporary Ethnography*, 19, 271-294.

Sanjana, P., Torpey, K., Schwarzwalder, A., Simumba, C., Kasonde, P., Nyirenda, L., … Thompson, C. (2009). Task-shifting HIV counselling and testing services in Zambia: The role of lay counsellors. *Human Resources for Health, 7*(44), 1-15.

Saravolatz L. D., Winslow, D. L., Collins, G., Hodges, J. S., Pettinelli, C., Stein, D. S., Abrams, D. (1996). Zidovudine alone or in combination with didanosine or zalcitabine in HIVinfected patients with the acquired immunodeficiency syndrome or fewer than 200 CD4 cells per cubic millimeter. *New England Journal of Medicine,* 335, 1099-106.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness*, 8, 26-43.

Scambler, G., & Hopkins, A. (1990). Generating a model of epileptic stigma: the role of qualitative analysis. *Social Science and Medicine*, 30, 1187-94.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness*, 8, 26-43.

Scambler, G. (2009). Health-related stigma. *Sociology of Health and Illness*, 31, 441-455.

Scandlyn, J. (2000) ‘When AIDS became a chronic disease’, *Western Journal of Medicine*, 172(2): 130-133.

Schneider. J., & Conrad, P. (1983). *Having epilepsy: the experience and control of illness.* Philadelphia: Temple University Press.

Schultz, A. (1967). *The phenomenology of the social world*. Evanston, IL: North-Western University Press.

Schwalbe, M., & Wolkomir, M. (2001). The masculine self as problem and resource in interview studies of men. *Men and Masculinities*, 4 (1), 90-103.

Seale, C. (2010). Death, dying, and the right to die. In C. E. Bird, P. Conrad, A. M. Fremont, & S. Timmerman (Eds.), *Handbook of Medical Sociology*. Nashville: Vanderbilt University Press.

Seeley, J., Mbonye, M., Kalanzi, I., Wolff, B., & Coutinho, A. (2012). HIV and identity: the experience of AIDS support group members who unexpectedly tested HIV negative in Uganda. *Sociology of Health and Illness*, 34(3), 330-344

Seeley, J., & Russell, S. (2010). Social rebirth and social transformation: Rebuilding social lives after ART in rural Uganda. *AIDS Care, 22*(1), 44-50.

Seeley, J., Russell, S., Khana, K., Ezati, E., King, R., & Bunnell, R. (2009). Sex after ART: Sexual partnerships established by HIV-infected persons taking anti-retroviral therapy in Eastern Uganda. *Culture, Health & Sexuality, 11* (7), 703-716.

Serpe, R. T. (1987). Stability and change in self: a structural symbolic interactionist explanation. *Social Psychology Quarterly*, 50, 44-55.

Setel, P. (1999). *A plague of paradoxes: AIDS, culture and demography in northern Tanzania*. Chicago: University of Chicago Press.

Sewell, W. (1992). A Theory of structure: Duality, agency, and transformation. *American Journal of Social Science,* 98(1), 1-29.

Sharp, S. (2017). Belief in miracles and attitudes towards voluntary euthanasia. *Death Studies, 41*(4), 211-219.

Shaw, I. (2008). Ethics and practice of qualitative research. *Qualitative Social Work*, 7(4), 400-414.

Shilling, C. (2003). *The body and social theory* (2nd ed.). London: Sage.

Shilling, C. (1993. *The body and social theory*. London: Sage

Shilling, C. (2001). Embodiment, experience and theory: In defence of the sociological tradition. *The Sociological Review*, 49(3), 327-344.

Shuper, P. A., Nueman, M., Kanteres, F. A., Baliunas, D., Joharchi, N. & Rehm, J. (2010). Causal considerations on alcohol and HIV/AIDS: a systematic review. *Alcohol and Alcoholism*, 45(2), 159-166.

Siegel, K., & Krauss, B. (1991). Living with HIV-infection: Adaptive tasks of sero-positive gay men. *Journal of Health and Social Behaviour*, 32 (3), 17-32.

Siegel, K., & Lekas, H. M. (2002). AIDS as a chronic illness: Psychosocial implications. *AIDS,* 16 (suppl 4), S69-S76.

Silverman, D. (2011). *Interpreting qualitative data: a guide to the principle of qualitative research*. London: Sage.

Silverman, D. (2013). *Doing qualitative research: a practical handbook*. London: Sage

Silverman, D. (Ed.).(1998). Qualitative research practice. London: Sage

Sikora, J., & Lewins, F. (2007). Attitudes concerning euthanasia: Australia at the turn of the 21st Century. *Health Sociology Review, 16*(1), 68-78.

Simbayi, L. C., Kalichman, S. C., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women in Cape Town, South Africa. *Sexually Transmitted Infections*, *83*(1), 29-34.

Simon, S. (1996). *Gender in translation: Cultural identity and the politics of transmission*. London: Routledge.

Simpson, R., & Simpson, A. (2018). Embodying dirty work: a review of the literature. *Sociology Compass*, 12(6), 1-9.

Skinner, D., & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social Aspects of HIV/AIDS*, 1(3), 157-164.

Smith, B. (2018). Generalizability in qualitative research: Misunderstandings, opportunities and recommendations for the sport and exercise sciences. *Qualitative Research in Sport, Exercise and Health*, 10(1), 137-149.

Smith, D. J. (2004). Youth, sin and sex in Nigeria: Christianity and HIV/AIDS-related beliefs and behaviour among rural-urban migrants. *Culture, Health and Sexuality, 6*(5), 425-437.

Smith, D. J. (2014). *AIDS doesn't show its face: Inequality, morality, and social change in Nigeria*. Chicago: The University of Chicago Press.

Smith, R. A., & Niedermyer, A. J. (2009). Keepers of the secret: Desires to conceal a family member's HIV-positive status in Namibia, Africa. *Health Commun., 24*(5), 459-72.

Smith, D.J (2003) Imagining HIV/AIDS: Morality and perceptions of personal risk in Nigeria, Medical Anthropology, 22:4, 343-372.

Smith, D. J. (2004). Youth, sin and sex in Nigeria: Christianity and HIV/AIDS-related beliefs and behaviour among rural-urban migrants. *Culture, Health and Sexuality*, 6(5), 425-437.

Smith, D. (2007). Modern marriage, men’s extramarital sex, and HIV risk in south-eastern Nigeria. *American Journal of Public Health*, 97(6), 997-1005.

Smith, D. J., & Mbakwem, B. C. (2010). Antiretroviral therapy and reproductive life projects: Mitigating the stigma of AIDS in Nigeria. *Social Science and Medicine*, 71(2), 345-352.

Smith, H. J. (2008). Language and rigour in qualitative research: Problems and principles in analyzing data collected in Mandarin. *BMC Medical Research Methodology*, 8(44), 1-8.

Smith, M. K., Power, K. A., Kashuba A. D., & Cohen, M. (2011). HIV-1 treatment as prevention: the good, the bad, and the challenges. *Current opinion in HIV and AIDS*, 6(4), 315–325.

Smith, R. (2007). Body, mind and spirit? Towards an analysis of the practice of yoga. *Body and Society*, 13(2), 25-46.

Sontag, S. (1989). *AIDS and its metaphor*. New York: Farrar, Strauss and Giroux

Sontag, S. (1978). *Illness as metaphors*. Harmondsworth: Penguin

Sparkes, A., & Smith, B. (2003). Men, sport, spinal cord Injury and narrative time. *Qualitative Research*, 3(3), 295-320.

Squire, C. (2010). Being naturalised, being left behind: the HIV citizen in the era of treatment possibility. *Critical Public Health*, 20 (4), 401-27.

Solórzano, L., & Glassgold, S. (2010). Powerful youth: Determining successful participation in an HIV support group for youth, social work with groups. (33)4, 288-303.

Speakman, S. (2012). Comparing the impact of religious discourse on HIV/AIDS in Islam and Christianity in Africa. *Vanderbilt Undergraduate Research Journal*, *8*, 1-6.

Sperling, D. (2020). *Suicide tourism: Understanding the legal. philosophical and socio-political dimensions*. Oxford: Oxford University Press.

Ssali, S. N., Atuyambe, L., Tumwine, C., Segujja, E., Nekesa, N., Nannungi, A., Ryan, G., & Wagner, G. (2010). Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: an exploratory study. *AIDS Patient Care and STDS*, 24(10), 675-681.

Stack, S. (1979). Durkheim's theory of fatalistic suicide: A cross-national approach. *The Journal of Social Psychology, 107*(2), 161-168.

Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W. Simbayi, C., Barre, I., … Dovidio, J. F. (2019). The health stigma and discrimination framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med, 17,* 31.

Staszak, J. (2008). *Other/otherness international encyclopaedia of human geography*. London, UK: Elsevier.

Stavrianakis, A. (2019). *Leaving: A narrative of assisted suicide*. Berkeley: University of California Press.

Steffen, V. (1997). Life stories and shared experience. *Social Science and Medicine*, 45 (1), 99-111.

Steglitz, J., Ng, R., Mosha, J. S., & Kershaw, T. (2012). Divinity and distress: the impact of religion and spirituality on the mental health of HIV-positive adults in Tanzania. *AIDS Behaviour*,16, 2392-8.

Steinberg, J. (2008). *Three-letter plague*. Johannesburg, South Africa: Jonathan Ball.

Stephen, S. H. (1999). Tobacco smoke, carcinogens and lung cancer. *JNCI: Journal of the National Cancer Institute*, 91(14), 1194–1210.

Stern, R., Puoane, T., & Tsolekile, L. (2010). An exploration into the determinants of noncommunicable diseases among rural-to-urban migrants in periurban South Africa. *Preventing Chronic Disease*, 7(6): A131.

Stevens, P.E., & Hildebrandt, E. (2009). Pill taking from the perspective of HIV-infected women who are vulnerable to antiretroviral treatment failure. *Qualitative Health Research,* 19(5): 593-604.

Steward W. T., Herek, G. M., Ramakrishna, J., Bharat, S., Chandy, s., Wrubel, J., & Ekstrand, M. L. (2008). HIV-related stigma: Adapting a theoretical framework for use in India. *Social Science and Medicine,* 67(8),1225-1235.

Stimson, G.V. (1974). Obeying doctor's orders: a view from the other side. *Social Science and Medicine*, 8, 97-104.

Stine, G. J. (2000). *AIDS Update 2000*. New Jersey: Prentice Hall.

Stott, H. (1959). Drug acceptability and chemoprophylaxis in under-developed countries. *Bulletin of International Union of Tuberculosis*, 29, 289.

Strauss, A., & Corbin, J. (1990) *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strauss, A., & Glaser, B. (1975). *Chronic illness and quality of life*. St. Louis: Mosby.

Strauss, A. (1959). *Mirrors and masks*. Mill Valey, CA: Sociology Press.

Strauss, R. (1957). The nature and status of medical sociology. *American Sociological Review*, 22, 200-4.

Strauss, M., Rhodes, B., & George, G. (2015). A qualitative analysis of the barriers and facilitators of HIV counselling and testing perceived by adolescents in South Africa. *BMC Health Service Research*, *15*(250), 1-12.

Strong, T. B. (1996). Nietzsche's political misappropriation. In B. Magnus & K. M. Higgins (Eds.). *The Cambridge companion to nietzsche*. Cambridge: Cambridge University Press.

Stutterheim, S. E., Shiripinda, I., Bos, A. E., Pryor, J. B., de Bruin, M., Nellen, J. F., ... Schaalma, H. P. (2011). HIV status disclosure among HIV-positive African and Afro-Caribbean people in the Netherlands. *AIDS Care, 23(20)*, 195-205.

Subero, G. (2014). *Representations of HIV/AIDS in contemporary Hispano-American and Caribbean culture: Cuerpos sui SIDAS*. Surrey: Ashgate Publishing Ltd.

Suwankhong, D., & Liamputtong, P. (2015). Cultural insiders and research fieldwork: case examples from cross-cultural research with Thai people. *International Journal of Qualitative Methods,* 1–7.

Sveen, U., Søberg, H. L., & Østensjø, S. (*2016*). *Biographical* disruption, adjustment and reconstruction of everyday occupations and work participation after mild traumatic brain injury: a focus group study. *Disability and Rehabilitation*, 38(23), 2296-304.

Swendemana, D., Ingram, B. L., & Rotheram-Borus, M. J. (2009). Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*, 21(10), 1321-1334.

Synnott*,* A. (*1993*). *The body social symbolism*, *self and society*. Routledge, London and New York.

Syvertsen, J. L., Bazzi, A. M., Scheibe, A., Adebajo, S., Strathdee, S. A., & Wechsberg, W. M. (2014). The promise and peril of pre-exposure prophylaxis (PrEP): Using social science to inform PrEP interventions among female sex workers. *African Journal of Reproductive Health*, 18(3), 74-83.

Tamuno, I. B., & Musa, B. M. (2011). Socio-demographic and symptomatic clinical profile of patients with HIV infection in a tertiary health care facility in north-western Nigeria. *International Journal of Pharmaceutical and Biomedical Research*, 2(3), 206-210.

Tartaro, C., & Lester, D. (2005). An application of Durkheim's theory of suicide to prison suicide rates in the United States. *Death Studies, 29*(5), 413-422.

Tausig, M. (2013). The sociology of chronic illness and self-care management.

Research in the Sociology of Healthcare, 31, 247-72.

Temple, B. (1997). Watch your tongue: Issues in translation and cross-cultural research. *Sociology*, *31*(3), 607-618.

Thoits, P. A. (2013). Self, identity, stress and mental health. In C. S. Aneshensel, J. C. Phelan and A. Bierman (Eds.), *Handbooks of Sociology and Social Research*, Springer: Dordrecht.

Tiendrebeogo, G., and Buykx, M. (2004). *Faith-based organisations and HIV/AIDS prevention and impact mitigation in Africa.* Bulletin of the Royal Tropical Institute 361: KIT Publishers

Tewksbury, R., & McGaughey, D. (1997). Stigmatization of persons with HIV disease: Perceptions, management, and consequences of AIDS. *Sociological Spectrum*, 17(1), 49-70.

Tewksbury, R. (1994). Speaking of someone with AIDS: Identity constructions of persons with HIV disease. *Deviant Behaviour*, 15 (4), 337-355.

Tewksbury, R., & McGarghey, D. (1998). Identities and identity transformation among persons with HIV disease. *International Journal of Sexuality and Gender Issues*, 3(3), 1566-768.

Thoits, P. A. (1991). On merging identity theory and stress research. *Social Psychology Quarterly*, 54(2), 101-112.

Titchen, A., & McIntyre, D. (1993). A phenomenological approach to qualitative analysis in nursing research. In A. Titchen (Ed.), *Changing nursing practice* *through action research*. Oxford: National Institute for Nursing, Centre for Practice Development and Research.

Tocco, J. U. (2010). Every disease has its cure: Faith and HIV therapies in islamic northern Nigeria. *African Journal of AIDS Research*, 9(4), 385-395.

Tocco, J. M. (2017). The islamification of antiretroviral therapy: Reconciling HIV treatment and religion in northern Nigeria. *Social Science and Medicine*, 190, 75-82.

Togarasei, L. (2010). Christian theology of life, death and healing in an era of antiretroviral therapy: Reflections on the responses of some Botswana churches. *African Journal of AIDS Research*, 9(4), 429-435.

Trevino, K. M., Pargament, K. I., Cotton, S., Leonard, A. C., Hahn, J., Caprini-Faigin, C. A., & Tsevat, J. (2010). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. *AIDS Behaviour*, 14, 379-89.

Trojan, A. (1989). Benefits of self-help groups: a survey of 232 members from 65 disease-related groups. *Social Science and Medicine*, 29, 225-232.

Trostle, J. A., Hauser, W., & Susser, I. S. (1983). The logic of non-compliance: Management of epilepsy from the patient's point of view. *Culture, Medicine and Psychiatry,* 7, 35-56.

Trostle, J. A. (1988). Medical compliance as ideology. *Social Science and Medicine*, 27(12), 1299-1308.

Tsai J. H., Choe, J. H., Lim, J. M., Acorda, E., Chan, N. I., Taylor, V., & Tu, S. (2004). Developing culturally competent health knowledge: Issues of data analysis of cross-cultural, cross-language qualitative research, *International Journal of Qualitative Methods*, 3(4), 2-14.

Tsarenko, Y., & Polonsky, M. J. (2011). You can spend your life dying or you can spend your life living: Identity transition in people who are HIV-positive. *Psychology and Health*, 26(4), 465-483.

Turner, B. S. (1996). *The body and society: Explorations in social theory* (2nd ed.).

London: Sage.

Turner, B. S. (1995). *Medical power and social knowledge*. London: Sage Publications,

Turner, B. S. (1997). Foreword: From governmentality to risk, some reflections on Foucault's contribution to medical sociology. In A. Petersen & R. Bunton (Eds.), *Foucault*, *Health and Medicine*. London: Routledge.

Twigg, J., Wolkowitz, C., Cohen, R. L., Nettleton, S. (2011). Conceptualising body work in health and social care. *Sociology of Health and Illness*, 33(2), 171-88.

Twinn, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing*, 6, 418-423.

Ucheaga, D. N., & Hartwig, K. A., (2010). Religious leaders' response to AIDS in Nigeria. *Global Public Health, 5*(6), 611-625.

Ugwu, F. O., & Ugwu, C. (2013). Anointing without money: Exploring the relationships between materialism, happiness and daily spiritual experience in a Nigerian sample. *International Journal of Asian Social Science*, 3(5), 1196-1207.

United Nations Programme on HIV/AIDS. (2009). *Epidemiological factsheet* on Nigeria. Geneva: UNAIDS.

United Nations Programme on HIV/AIDS. (2013). Global Report on AIDS epidemic.

Geneva: UNAIDS.

United Nations Programme on HIV/AIDS. (2005). Africa Fact Sheet on HIV/AIDS.

Geneva: UNAIDS.

United Nations Programme on HIV/AIDS. (2009). Fact sheet about HIV treatment.

Geneva: UNAIDS.

United Nations Programme on HIV/AIDS (UNAIDS). (2019). Survey results. Retrieved April 5 2021, from UNAIDS website: http://aidsinfo.unaids.org/.

United Nations Programme on HIV/AIDS (UNAIDS). (2020). People living with HIV receiving ART. Retrieved April 5 2021, from UNAIDS website: http://aidsinfo.unaids.org/.

Usadolo, S. E. (2019). Christians' perceptions of HIV prevention in Benin City, Nigeria: Implications for HIV/AIDS communication. *Cogent Medicine*, *6*(1), 1658957.

Valdiserri, R. O. (2002). HIV/AIDS stigma: An impediment to public health. *Am J Public Health., 92*(3), 341-342. PMID:11867303.

Van Damme, W., Kober, K., & Laga, M. (2006). The real challenges for scaling up ART in sub-Saharan Africa. *AIDS*, 20, 653-656.

Vanhove, G. F., Schapiro J. M., Winters, M. A., et al. (1996). Patient compliance and

drug failure in protease inhibitor monotherapy. *JAMA*, 276, 1955-1956.

Vasilachis de Gialdino, I. (2009). Ontological and epistemological foundations of qualitative research*. FORUM: Qualitative Social Research*, 10(2), Art. 30.

Vaughan, M. (1991). *Curing their ills: Colonial power and African illness*. Stanford, California: Stanford University Press.

Veen, M., te Molder H. F., Gremmen, B. et al. (2010). Quitting is not an option: an

analysis of online diet talks between celiac disease patients. *Health*, *14*(1), 23-40.

Vella, S. (2012). The history of antiretroviral therapy and of its implementation in resource-limited areas of the world. *AIDS*, 26,1231-124.

Vermeire, E., Hearnshaw, H., Van Royen, P. et al. (2001). Patient adherence to treatment: Three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics*, 26, 331-342.

Vernazza, P. (2009). The debate continues: Does undetectable means uninfectious? *HIV Therapy*, 3(2), 113-116.

Vernazza, P., Hirschel, B., Bernasconi, E., et al. (2008). Les personnes se´ropositives ne souffrant d'aucune autre MST et suivant un traitement antire´troviral efficace ne transmettent pas le VIH par voie sexuelle. *Bulletin des Me´decins Suisses*, 89(5),165-9.

Ville, I. (2005). Biographical work and returning to employment following a spinal cord injury. *Sociology of Health and Illness*, 27(3), 324-50.

Visser, M., BPsych, J. M., de Villiers, A., Sikkema, K., & Jeffery, B. (2005). Development of structured support groups for HIV-positive women in South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 2*(3), 333-343.

Viswanathan, H., & Lambert, B. L. (2005). An inquiry into medication meanings, illness, medication use, and the transformative potential of chronic illness among African Americans with hypertension. *Research in Social and Administrative Pharmacy*, 1(1), 21-39.

Volberding, P. A., Lagakos, S. W., Koch, M. A. et al. (1990). Zidovudine in asymptomatic human immunodeficiency virus infection. A controlled trial in persons with fewer than 500 CD4-positive cells per cubic millimetre. The AIDS clinical trials group of the National Institute of Allergy and Infectitious diseases. *New England Journal of Medicine*, 322, 941-949.

Volberding, P. A., & Deeks, S. G. (2010). Antiretroviral therapy and management of HIV infection. *The Lancet*, 376 (9734), 49-62.

Waaijman, K. (2007). What is spirituality? *Acta Theologica Supplementum*, 8, 1-18.

Wainwright, S. P., & Turner, B. S. (2004). Epiphanies of embodiment: Injury, identity and the balletic body. *Qualitative Research*, 4(3), 311-37.

Walby, S. (1996). Woman and nation. In G. Balakrishnan (Ed.), *Mapping the nation*. London: Verso.

Walker, K., & Pope, J. (2012). Treatment of systemic sclerosis (SSc) complications: What to use when first-line treatment fails. A consensus of SSc experts. *Semin Arthritis Rheum*, 42, 42-55.

Wang, J. (2006). Questions and the exercise of power. *Discourse and Society*, 17, 259-548.

Watson, J. (2000). *Male bodies: Health, culture and identity*. Buckingham: Open University Press.

Wasserman, J., Clair, J. M., & Ritchey, F. J. (2005). A scale to assess attitudes toward euthanasia. *Omega Journal of Death and Dying, 51*, 229-237.

Wasserman, J., Clair, J. M., & Ritchey, F. J. (2006). Racial differences in attitudes towards euthanasia. *Omega Journal of Death and Dying, 52*(3), 263-287.

Weidle, P. J., Ganea, C. E., Ernst, J., et al. (1998). *Multiple reasons for nonadherence to antiretroviral medications in an inner-city minority population: Need for a multifaceted approach to improve adherence*. Geneva: World AIDS Conference publication.

Weiss, R. A. (1996). HIV receptors and the pathogenesis of AIDS. *Science*, 272, 1885-86.

Weitz, R. (1989). Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behaviour*, 30, 270-281.

Wekesa, E., & Coast, E. (2013). Living with HIV postdiagnosis: a qualitative study of the experiences of Nairobi slum residents. *BMJ Open*, 3, e002399.

Wensing, A.M et al. (2010) 'Fifteen years of HIV Protease Inhibitors: raising the barrier to resistance', *Antiviral Research*, 85(1): 59-74.

Wet, K., & Wouters, E. (2006). Identity and the body: Narrative accounts of two HIV-positive women with lipodystrophy in post-apartheid South Africa. *Social T heory and Health, 14,* 351-371.

Weyers, H. (2006). Explaining the emergence of euthanasia law in the Netherlands: How the sociology of law can help the sociology of bioethics. *Sociology of Health and Illness, 28*(6), 802-816.

White, L. (2000). *Speaking with vampires: Rumour and history in colonial Africa.* Berkeley, California: University of California Press.

Whitehead, L. C. (2005). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science and Medicine*, 62(9), 2236-45.

Wiedenmann, A., & Weyerer, S. (1994). Testing Durkheim's theory of suicide: Additional results from Germany. *Eur Arch Psychiatry Clin Nuerosci*, *244*, 284-286.

World Health Organisation. (2005). *Preventing chronic diseases. Preparing a health care workforce*. Geneva: World Health Organization (WHO).

World Health Organisation. (2013). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*. Geneva: World Health Organisation (WHO).

World Health Organisation. (2015). *Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV*. Geneva: World Health Organisation (WHO).

World Health Organisation. (2017). *Global Health Observatory Data on HIV*. Retrieved from http://www.who.int/gho/hiv/en/. Accessed on 11th March 2018.

World Health Organisation. (2017). Report on HIV/AIDS and antiretroviral therapy. Retrieved from http://www.who.int/hiv/topics/treatment/en/index.html

Williams, G. (1989). Hope for the humblest: the role of self-help in chronic illness. The case of ankylosing-spondylitis. *Sociology of Health and Illness*, 11, 135-159.

Williams, C. L., & Heikes, E. J. (1993). The importance of researcher's gender in the in-depth interviewing: Evidence from two case studies of male nurses. *Gender and Society*, 7(2), 280-91.

Williams, G. (1984). The genesis of chronic illness: Narrative reconstruction. *Sociology of Health and Illness*, 6, 175-200.

Williams, G., & Popay, J. (1994). Lay knowledge and the privilege of experience. In J. Gabe, D. Kelleher and G. Williams (Eds.), *Challenging Medicine*. London: Routledge.

Williams, S. J. (2000). Chronic illness as biographical disruption or biographical

disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22(1), 40-67.

Williams, S. J., & Bendelow, G. A. (1998). *The lived body: Sociological themes, embodied issues*. London: Routledge.

Williams, S. J. (1996). The vicissitudes of embodiment across the chronic illness

trajectory. *Body and Society*, *2*(2), 23-47.

Williams, S. J. (2003). *Medicine and the body*. London: Routledge.

Wilson, T. D., & Meyers, J. (2001). Lessons from the past: Do people learn from experience that emotional reactions are short-lived? *Personality and Social Psychology Bulletin*, 27 (12), 1648-1661.

Wilson, S. (2007). When you have children, you're obliged to live: Motherhood, chronic illness and biographical disruption. *Sociology of Health and Illness*, 29(4), 610-626.

Wituk, S., Shepherd, M. D., Slavich, S., Warren, M. L., & Meissen, G. (2000). A topography of self-help groups: an empirical analysis. *Social Work*, 45(2),157-65.

Wong, W. K., & Ussher, J. (2008). How do subjectively-constructed meanings ascribed to anti-HIV treatments affect treatment-adherent practice? *Qualitative Health Research*, 18 (4), 458-468.

Wynn, G. H., Zapor, M. J., Smith, B. H., Wortmann, G., Oesterheld, J. R., Armstrong, S. C., & Cozza, K. L. (2004). Overview, history, and focus on protease inhibitors. *Psychosomatics*, 45(3), 262-270.

Wynne, B. (1996). May the sheep safely graze? A reflexive view of the expert-lay knowledge divide. In S. Lash, B. Szerszynski and B. Wynne (Eds.), *Risk, environment and modernity. Towards a new ecology*. London: Sage.

Yahaya, L. A., Jimoh, A. A., & Balogun, O. R. (2010). Factors hindering acceptance of HIV/AIDS voluntary counselling and testing (VCT) among youth in Kwara State, Nigeria. *African Journal of Reproductive Health*, 14(3), 159-164.

Yinhua, X. (2011). Equivalence in translation: Features and necessity. *International Journal of Humanities and Social Science*, 1(10), 1-3.

Young, I., Flowers, P., & McDaid, L. (2016). Can a pill prevent HIV? Negotiating the biomedicalisation of HIV prevention. *Sociology of Health and Illness*, 38(3), 411-425.

Young, I., Davis, M., Flowers, P., & McDaid, L. M. (2019). Navigating HIV citizenship: Identities, risk and biological citizenship in the treatment as prevention era. *Health, Risk and Society*, 21(1-2), 1-16.

Young, A., (1982). The anthropologies of illness and sickness. *Annual Reviews of Anthropology*, 11, 257-285.

Young, I., & McDaid, L. (2014). How acceptable are antiretrovirals for the prevention of sexually transmitted HIV? A review of research on the acceptability of oral pre-exposure prophylaxis and treatment as prevention. *AIDS and Behaviour*, 18(2), 195-216.

Zhang, Y., & Wildemuth, B. M. (2006). *Unstructured interviews*. Retrieved May 2, 2018 from https://www.ischool.utexas.edu/~yanz/Unstructured_interviews.pdf

Zhou, A (2019). Therapeutic citizens and clients: Diverging healthcare practices in Malawi's prenatal clinics. *Sociology of Health & Illness*, 41(4), 625-642.

Zierler, S., Cunningham, W. E., Andersen, R., Shapiro, M. F., Bozzette, S. A., Nakazono, T., … St.Clair, P. (2000). Violence victimization after HIV infection in a US probability sample of adult patients in primary care. *American Journal of Public Health, 90*(2), 208-215.

Zola, I. (1981). Structural constraints in the doctor-patient relationship: the case of non-compliance. In L. Eisenberg and Kleinman (Eds.), *The relevance of social science for medicine*. Boston, MA: D. Reidel Publishing.

APPENDICES

Appendix 1: Participant I formation Sheet

INFORMATION LEAFLET

***in a project to explore users' accounts and experience of taking antiretroviral therapy.

How can you help?

I am carrying out a project to find out about the users' experience of antiretroviral therapy.

I will like to invite you to take part in this project by talking about your own story, of using of living with HIV and taking antiretroviral drugs, so that I can understand a little better the experiences you had, and help towards developing measures to assist in the future.

What is the project about?

The project aims to investigate the experiences of people living with HIV/AIDS with antiretroviral therapy. The project will use these stories to explore the way in which HIV patients use antiretroviral therapy, engage in antiretroviral treatment and health service, and understand the kinds of activities that people living with HIV do with their medication and around their health.

Why have I been asked to take part?

It is important for us to include the views of people living with HIV/AIDS who are currently on antiretroviral therapy, with a view to understanding the kinds of activities that people living with HIV do with their medication and around their health. I am approaching you to see if you would like to take part.

What is involved?

If you agree to take part, I will organise a meeting with you at the conference room of your support group's secretariat, to ask you some questions about your health experience before and after HIV diagnosis, treatment history and experiences of antiretroviral medication usage. It is your own unique story that I am interested in.

You will also be asked to sign a consent form prior to the interview. The interview is likely to last around an hour, but it can be shorter if this is more time you can spare.

If you agree, our conversation will be audio-recorded and transcribed (typed up) in order for it to be used as part of the project.

Do I have to take part?

You do not have to take part. If you do decide to take part, you can change your mind at any time. You do not need to give a reason.

Will you tell anyone else what I say?

Only the researcher will know your personal information and views. All identifying information will be removed from interview records.

Your name will NOT be mentioned to others or published in any of our reports, and great care will be taken to ensure your views and personal information is not identifiable.

How will the information I provide be used?

The findings will be used for the completion of a PhD project that will be instrumental towards enhancing sociological knowledge on HIV management and using its findings to understand how treatment can be integrated into personal and social fabric of ill-persons in relations to the management of their illness condition. This will include anonymised information provided by everyone who agrees to take part in the project.

A summary of the project will be available to all participants.

How do I know this project is professional and safe?

The project has been scrutinised by the Royal Holloway, University of London Research Ethics Committee. For more information, you can please contact the Secretary of the University Research Ethics Committee by emailing ethics@rhul.ac.uk or telephone +441784 414930

Who is the researcher?

Ayodeji Bayo Ogunrotifa, a trained social researcher, is conducting the investigation for a PhD project. You can find out more about Ayodeji by visiting his university webpage: **https://pure.royalholloway.ac.uk/portal/en/persons/ayodeji-ogunrotifa(e1966ff6-464c-4037-af12-4830656f5447).html**

Ayodeji is working closely with Prof. Jonathan Gabe and Dr Alex Dymock at Royal Holloway, University of London to ensure the project is conducted in an ethical and sensitive manner that does not impinge on participants or their families. You can find out more about Jonathan Gabe on his webpage, **https://pure.royalholloway.ac.uk/portal/en/persons/jonathan-gabe(a61d244e-30d3-45cf-b875-0402ff7df267)/persons.html?ordering=personOrderByLastName&pageSize=10&page=0&descending=true**

For more information

If you would like more information about the project, or have concern about certain aspects of the project, please contact Ayodeji by phone on **+2347058671097**, by email at Ayodeji.Ogunrotifa.2008@live.rhul.ac.uk, or by sending the Response Form included.

Appendix 2: Consent Form

School of Law
Royal Holloway, University of London
Egham, Surrey TW20 0EX
http://www.rhul.ac.uk/law

Administrative Office
Moore Building, MB0-10
+44 (0) 1784 414085

ROYAL
HOLLOWAY
UNIVERSITY
OF LONDON

Healthwork and the experience of antiretroviral medications in everyday life.

CONSENT FORM

Please read and answer every question.

TO COMPLETE	**YES**	**NO**
Can you confirm that you have read the Information Leaflet and that you understand what the project is about and what taking part involves?	☐	☐
Do you understand that your participation is entirely voluntary and that you are free to withdraw at any time without giving a reason?	☐	☐
Do you understand that your name will not be identified and that the information you share will not be given to anyone else but used as quotes in this study's publication?	☐	☐
Would you like to take part in the project?	☐	☐
If yes, do you agree to your interview being recorded?	☐	☐
If yes, are you happy for your data to be stored for up to 3 years after the completion of the project to allow the researcher to undertake further research if required.	☐	☐

Are you happy to be contacted in the future to take part in additional research projects that may occur after the current project has been completed?	☐	☐

Participant's Name: ....

Participant's Signature: ....

Researcher's Name: ....

Researcher's Signature: ....

Date of Interview: ....

Appendix 3: Interview Topic Guide

Interview Topic Guide

Core Topics: Healthwork, Medication use, biographical time, body, self/identity, Healthcare professionals.

● To start, can you tell me a bit about yourself?

  - How long have you been living with HIV?
  - Apart from HIV, what other health issues/conditions do you have?
  - How often do you disclose your condition with family members and others?

Healthwork

● Can you tell me a bit about what happened around the time that you first became diagnosed with HIV?

  - When did you get diagnosed?
  - After being diagnosed with HIV, could you please tell me what steps do you take to look after your health?
  - Since you have been receiving treatment, can you please tell me what steps have you taken improve your health?
  - What kind of activities have you been engaging with to make your condition invisible to others?
  - Can you please describe how you have been managing your condition since being diagnosed?

Treatment

  - What information did doctor/nurse tell you about HIV?
  - What sort of treatment is given to you as HIV patient?
  - How often did you visit hospital?
  - Do you visit hospital with doctors' appointment?
  - What prompts you to visit hospital without doctor's appointment?
  - How often do you keep appointment with doctors at mutually agreed time?
  - If you missed your appointment, how do you make up for the lost appointment?
  - What kind of experience have you had in dealing with physicians and other health care professionals when you visited hospital?

● What did the doctor recommend in terms of treatment or treatment options?

  ¯ How much time were you given to make a decision?

  ¯ Did you look for additional, and if so, where?

  ¯ Were the opinions of people around you significant in deciding on your course of treatment?

  ¯ Why did you decide to have the treatment that you did?

  ¯ How long after your decision did treatment begin?

  ¯ What did the treatment involve?

  ¯What are the information associated with the kind of drugs you were given?

  ¯ How did the treatment fit with your personal/family and work life?

  ¯ How if at all, did things change in your personal/family and work life?

  ¯ Did having treatment put any strain or pressure on your personal/family and work life?

  ¯ How was your day-to-day life affected by the treatment?

  ¯ Under what circumstance have you find it difficult to use your medications as prescribed by doctor?

  ¯ Do you at any time modify the way you are told to use your medications?

  ¯If so, why did you continue to stick to the prescribed drugs and its timing?

  ¯Is there any circumstances where you changed the type of drugs you are using?

  ¯ Apart from hospitals/health care facilities, where do you often consult for treatment? ¯ What types of support do you receive from those places?

The body and Medication Use

● Do you experience any bodily pain or serious illness that resulted to being diagnosed with HIV?

  ¯If so, how has this bodily pain or serious illness affected your everyday life?

  ¯ What impact does treatment have on your body?

  ¯ How did the body feel, both at the time and shortly following the treatment?

  ¯Can you please tell me how your body responded to treatment the first day you started using these drugs?

  ¯Can you tell me the experience you had in your body, one year after using these medications?

¯Since you have been using these medications, can you describe how your body feels and the experience you have got?

-Do you think all the overall activities you have undergone since being diagnosed with HIV have effect on your body or the way you perceive your body?

Self and Identity

● What was your response when you are told that you have been diagnosed with HIV?

¯ How was your diagnosis affected the way you see the world?

¯After being told of your diagnosis with HIV, what adjustment do you make about your life?

¯ With treatment, Is the view about yourself different now compare to when you are first diagnosed? If so, how?

¯ What changes do you think these treatments have brought to your worldview and yourself?

- Do you think all the overall activities you have undergone since being diagnosed with HIV have effect on how you now look at yourself and the world?

Biographical Time

● Can you please tell me about your life, work, career, education?

¯ Before being infected with HIV, what are your plans, aspirations, ambitions, etc you had?

¯ How do you plan to achieve those ambitions then?

¯ What kinds of activities and events do you enjoy doing before being infected with HIV?

¯ What kinds of activities are you doing presently?

¯ Do you think being diagnosed with HIV has disrupted your plans and aspirations? If so, how?

¯ Do you think antiretroviral drugs has helped you to think about these plans again or enable you to pursue them? If so, how?

¯How will you describe your past lives without HIV? How will you describe your present lives with HIV?

¯ Now that you are using antiretroviral drugs, how will you describe your future plans and ambitions?

¯ Do you think antiretroviral treatment will help you to achieve them? If so, why?

¯At what age do you think individuals can live on earth?

¯ What reasons can you attribute to this life expectancy?

¯ Before being diagnosed with HIV, what is your expectation about the age you will live on earth?

¯ When you are told that you have been diagnosed with HIV, what level of expectation do you have about the age you will live on earth?

¯Since you have been using these drugs, has your level of expectation about the time you will live on earth changed?

-Do you think all the overall activities you have undergone since being diagnosed with HIV have effect on how you look at your past, present and future?

Do you think all the overall activities you have undergone since being diagnosed with HIV have effect on your future plans, career and aspirations?

Appendix 4: Response Form

School of Law

Royal Holloway, University of London
Egham, Surrey TW20 0EX
http://www.rhul.ac.uk/law

Administrative Office
Moore Building, MB0-10
+44 (0) 1784 414085

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Healthwork and the experience of antiretroviral medications in everyday life.

RESPONSE FORM

If you are interested in taking part in this project please complete the following and return to the Coordinator through the enclosed stamped-addressed envelope.

TO COMPLETE

Name: ....

	YES	NO
I am happy to take part in the project	☐	☐

If you have selected yes above, please provide your personal and contact details below:

Telephone: .... Email: ....

Preferred Contact: PHONE ☐ EMAIL ☐ No Preference ☐

Where would you like the interview to take place? ....

What day/month would you like the interview to take place? ....

Optional information if you are happy to provide it at this stage:

Occupation: .... Age: .... Gender: ....

Marital Status: .... Children (Number): How long have you been using antiretroviral drugs……………………….

If you require further information about the project please contact Ayodeji on

+2347058671097 or email at: Ayodeji.Ogunrotifa.2008@live.rhul.ac.uk

Appendix 5: Ethics Application Letter Ondo State (Nigeria)

School of Law
Centre for Criminology & Sociology
Royal Holloway, University of London
Egham, Surrey TW20 0EX
http://www.rhul.ac.uk/law

Arts Building, F20
+44 (0) 1784 276614
j.gabe@rhul.ac.uk

12th January 2018

The Chairman,

Ondo State Health Management Board

Quarter 74, Alagbaka

Akure

Ondo State

Nigeria

REQUEST FOR PERMISSION TO CONDUCT RESEARCH WITH HIV-SUPPORT GROUPS IN STATE HOSPITALS IN AKURE.

Dear Sir,

My name is Ayodeji Ogunrotifa and I am a PhD student at the School of Law, Royal Holloway University of London. The research I wish to conduct for my doctoral thesis involves understanding the Healthwork of people living with HIV and their experience of antiretroviral therapy in everyday life. This research is conducted under the supervision of Professor Jonathan Gabe and Dr Alex Dymock of the School of Law, Royal Holloway University of London.

I am aware that HIV-support groups are formed at the hospitals where people living with HIV receive their medications. Therefore, I am hereby seeking your consent to approach a number of hospitals and HIV-support groups under the supervision of your board, to have access to the participants in support groups for this project.

I have furnished with this letter: a copy of Participants Information Leaflet, Interview Topic Guide, Consent form, Response form to be used in this research process, as well as a copy of the email approval that I received from Royal Holloway University Research Ethics Committee.

Upon completion of the study, I undertake to provide the board with a hard copy of the full research report. If you require any further information, please do not hesitate to contact me via the contact information provided on Participants' Information leaflet.

Thanks for your time and consideration in this matter.

Yours Sincerely

Ayodeji Ogunrotifa

Appendix 6: List of Developed Codes

(Please Note: this includes themes and sub-themes)

Healthwork

Religiosity

Sacred

Profane

Testing

Pre-treatment testing

Post-treatment testing

Counselling

Pre-treatment counselling

Post-treatment counselling

Concealment

Secrecy

Hiding treatment

HIV non-disclosure

Cultural understanding of HIV

Stigmatisation

Marginalisation

HIV-related violence

HIV-related violence

Support group participation

Dieting

Information gathering

Information sharing

Internet use

Corporeality

HIV corporeality

Infectious corporeality

Non-infectious corporeality

Normalised bodies

Partially normalised bodies

Risky bodies

Otherness

Dirty body

Risk

Biographical time

Past

Present

Future

Biographical disruption

Old biographical plans

Education

Career

Finance

Travelling

Biography

Relationship/Marriage

Continuity

Discontinuity

Reorganisation

Unattainability

New biographical plans

Readjustment

Acceptance

Rejection

Embodied agency

Infectious body

Othering/otherness

Corporeal changes

Cultural schema

Spiritual pollution

Reassessment

Negotiation

Reflexivity

Undetectability

Untransmittability

Embodiment

Essential social practices

Non-essential social practices

Religious inscription

Biomedical frame

Self

Identity

HIV identity

Existing Identities

Pre-diagnostic self

Post-diagnostic self

Accommodation

Stigmatised identity

Unhealthy identity

Felt stigma

Enacted stigma

Unhealthiness

Medication use

Valued self

Less valued self

Quest for survival

Will to live with condition

Denial

Diagnosis

Hopeless self

Powerless self

Hopelessness

Lack of optimism

Worldview

Meaninglessness

Incurable

Social exclusion

Lack of autonomy

Lack of control

Restricted lifestyle

Therapeutic requirement

Empowered self

Bracketing off

Confidence

Self worth

Self esteem

Disenchantment

Resources

Lay expertise/knowledge

Lay people

Praying

Viral load testing

CD_4 count testing

Adherence

Expert language

Expert/Professional knowledge

Compliance

Opportunistic infections

First-line therapy

Second-line therapy

Third-line therapy

Side-effects

Immunity

Discipline regime

Dieting routine

Health maintenance

Lay network

Comfort

Solace

Self representation

Sense of adjustment

Coping strategies

Practical advice

Lived experience

Participation

Seeking information

The new present

Living in the past

Living in the uncertain future

Uncertainty

Biographical destruction

Rough life

Worried future

Curative future

Redirection

Apprehension

Minimisation

Demythologisation

Religiosity

Loss of religious hold

De-othering

Introspection