

**IDENTITY, GOVERNMENTALITY, CHRONICITY AND  
DEVELOPMENT: A STUDY OF ZAMBIAN TEACHERS  
LIVING WITH AND AFFECTED BY HIV AND  
'THERAPEUTIC CITIZENSHIP'**

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## **Abstract**

This research examines the nature and processes of the ‘therapeutic citizenship’ status acquired by HIV positive schoolteachers who are on antiretroviral therapy (ART), and further ascertains this status’s implications for Zambia’s national development prospects. Teachers, who are a key group for those prospects, are disproportionately affected by ART. The theoretical frames of identity, chronicity and governmentality are explored and used as lenses through which the therapeutic citizenship of teachers living with HIV and ART can be understood and appropriated. Additionally, the concept of *ubuntu*, derived from African philosophies, is used to decipher values and virtues of human community. Semi-structured interviews with 41 HIV positive teachers in Zambia aged 25–55 were conducted. Transcripts were processed using NVivo Pro 12, and a thematic analysis was employed operating at three levels, using elements of discourse analysis at the two higher levels. The findings show that reported experiences of being on ART are affected by demographic factors such as location, age and gender. About 70% of participants described their health from a physical point of view, thus excluding mental-health issues caused by the ongoing uncertainties of HIV citizenship. Over 50% of participants found living on ART socially disruptive and medically difficult. For instance, the unending treatment practices around HIV were associated with positionings within a supportive biomedical citizen-state contract around ART, in relation to (de)professionalisation, in relation to ‘accepting’ or resisting lifelong medication, and in relation to citizenship within ‘pharmaceutical colonialism’. However, living with ART also increased pride in what the teachers’ students were achieving, making their HIV less relevant and perhaps less stigmatising. I argue in this thesis that being HIV positive and on ART in Zambia can create a specific form of ‘therapeutic citizenship’. This form of citizenship appears to be shaped by the importance of improving relationships between patients and clinic personnel, by community-based health care, by past experiences and present events, and by ongoing uncertainties about the future. Therefore, HIV citizenship can have both positive and negative influences on national development for a low-income country such as Zambia.

**Keywords:** Antiretroviral Treatment, HIV, Therapeutic Citizenship, Normalisation, National Development, Ubuntu, Zambia.

## **Declaration**

I declare that this research entitled: *Identity, Governmentality, Chronicity and Development: A Study of Zambian Teachers Living with and affected by HIV and 'Therapeutic Citizenship'*, is a product of my own work. With exceptions of where others' ideas or sources have been used in this thesis, appropriate citations are made, and full acknowledgement is provided in the references list.



26<sup>th</sup> July 2019

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## **Acronyms**

AATAZ	Anti-AIDS Teachers Association of Zambia
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CD4	Cluster of Differentiation 4
DEBS	District Education Board Secretary
GEA	Global Education for All
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
IPA	Interpretive Phenomenological Analysis
MDGs	Millennium Development Goals
MOE	Ministry of Education
MOH	Ministry of Health
NAC	National AIDS Council
NGOs	Non- Governmental Organisations
QoL	Quality of Life
SDA	Seventh Day Adventist
SDGs	Sustainable Development Goals
SSA	sub-Saharan Africa
UEL	University of East London
UN	United Nations
UNESC	United Nations Economic and Social Council
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNZA	University of Zambia
UREC	University (of East London) Research Ethics Committee
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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## Chapter one

### Introduction<sup>i</sup>

*So much has changed since 1997, but a few things remain – there is no cure for [HIV] AIDS, only treatment to prolong lives. The best one can do if not infected is prevent getting infected. As for those already infected, take your medication religiously to live a long, healthy and productive life. I am just one testimony of how much science and medicines have improved.*

Hon. Princess Kasune, politician and elected member of parliament in Zambia,  
23 years of living with HIV

#### 1.0 Overview

Ever since the creation of antiretroviral therapy (ART), traditional medical practitioners and scholars who examine the contingencies of progress in human immune deficiency virus (HIV) treatment have generally failed to engage with the social dimensions of medical normalcy for those living with a chronic health condition (De-Graft et al., 2010; Lock and Nguyen, 2018; Larsen, 2016). Despite the short-term as well as long-term effects of epidemics, the process of medicalisation has rarely been scrutinised as a category or effectively normalised, from either a theoretical or an empirical perspective.

This first chapter introduces the key question that this study addresses, and background information is given. This study examines the nature of medicalisation, the extent to which it makes HIV positive schoolteachers in Zambia acquire therapeutic citizenship status, and the implications this might have for development. The consequences and processes of living with a long-term chronic condition – the social concerns and political trajectories – are articulated around therapeutic citizenship for HIV positive teachers in Zambia. Further, the chapter outlines the methodological and theoretical contributions of this study.

This chapter is divided into four sections. First, background information for the study is briefly discussed. Second, it states the study's problem, research questions and objectives. Third, some preliminary conceptual information and the rationale of the study are outlined. In the fourth section, the context of the methodology is given. A

summary is given and the aim of each chapter is highlighted; additionally, the thesis structure is shown.

## **1.1 Background**

The United Nations' Sustainable Development Goals (SDGs) aim to eradicate poverty in 15 years. SDG number three focuses on 'good health and well-being' (WHO, 2016). The target under this goal is to reduce HIV and other diseases. HIV/AIDS is still a national disaster and a hindrance to development for many sub-Saharan African (SSA) states (Kharsany et al., 2016). The integration of Millennium Development Goals into the monitoring and evaluation process of the current SDGs has seen most African nations, including Zambia, make progress in the fight against HIV/AIDS (D'Alessandro and Zulu, 2017; Vorkoper et al., 2018). Although the combined efforts of international and local stakeholders to achieve the SDGs have reduced the threat of communicable and infectious diseases, the challenges of chronic conditions such HIV have short-term and long-term effects on social, economic and cultural factors in national development.

Actions for HIV testing and treatment programmes around the world have been integrated by UNAIDS programmes – for example, to reach the UNAIDS 90-90-90 goals by 2020 (see chapter two for a detailed explanation of these goals). Furthermore, the World Health Organisation (WHO) came up with new guidelines on treatment, recommending that treatment should be administered to all people living with HIV as soon as they are diagnosed, and irrespective of their cluster of differentiation 4 (CD4) count – which is often used as one of the yardsticks for normalising HIV through medicalisation (WHO, 2015). Ren (2002) defines medicalisation as a social practice which transforms behavioural, emotional and physiological human conditions into an entirely medical problem of Western medicine. The medicalisation of HIV and indeed other chronic health conditions is a process, but there can be degrees of using medication, as a cure or for functional health. Similarly, normalisation is both medically oriented – as individuals on ART when treated are 'normal' physiological bodies – and social, when regardless of treatment (although usually treatment is seen to play a role in this) they are seen as 'normal' citizens, people 'just like us' (Squire, 2013:90–104).

'Medicalisation' is used here to denote a process of sophisticated medical treatment. This view of process in medicine fits with notions of governmentality. Foucault

introduced the term ‘medicalisation’ with reference to politically charged medical interventions during the 18<sup>th</sup> century (Bulley, 2014). He argued that human existence, behaviours and bodies were brought into an increasingly dense and important network of medicalisation that allowed fewer and fewer things to escape (Foucault, 2008). As a concept, medicalisation describes direct and indirect medical processes and other techniques by which the state, civil society and medical practitioners lead and control individuals without being responsible for any unexpected outcomes. It is through these wide-ranging and often invisibilised techniques that the treatment of HIV is done. Therefore, the idea of ‘post-treatment’ or ‘post-AIDS’, identified in literature such as Tsampiras (2017), is questionable in expositions of medicalisation and normalisation, because people with HIV negotiate normalcy through medical interventions in long term of this ‘treatment’ era.

The pharmacological breakthrough on HIV/AIDS treatment is undeniably a medical success. The provision of ART places HIV somewhere between a disappearing tragedy – with some continuing effects of that history – and a treatable pandemic with ongoing socio-economic effects (Mweemba, 2008; Stillwaggon, 2001; Lichtenstein, 2015). For example, the psychosocial goals set in the fight against HIV include, among other things, stigma reduction. Stigma is often taken as the labelling and devaluing of individuals based on undesired differences that then increase social isolation (Goffman, 1963). HIV treatment has reduced but not removed stigma due to the social acceptance that comes with the healthy physical appearance of HIV positive people who are on ART. This reduction in stigma, however, does mean an absence of adverse reactions from others towards a condition that requires ART. When the medical requirements of a person are revealed, the stigma moves from the disclosable – which is physical – to the invisible, which is social (Squire, 2007:123).

Some gains have been recorded in the fight against the pandemic in Zambia. However, the disease still poses a severe threat, with different effects on individuals’ well-being and on national development in sectors such as agriculture, mining, health and tourism – as well as education (CSO, 2014), the focus of this thesis. Zambia may not meet the 2030 health-related SDGs and the Global Education for All (GEA) deadline. For example, this study highlights the well-being and development of HIV positive teachers in Zambia, exemplifying the relationship between health and education, which is often

overlooked. Education, and the resulting economic growth and social development, relies on a critical mass of healthy teachers. Sachs (2002) contends that HIV/AIDS, even in the treatment era, seems to be a major barrier to development.

Given the assumed socio-economic implications of the pandemic, there is no scope to escape the necessities of therapeutic citizenship. The notion of therapeutic citizenship is useful, as it allows unrecognised phenomena to be named, described and brought into collective claims (Petryna, 2010; Nguyen, 2008). ‘Therapeutic citizenship’ is a phrase that highlights the biopoliticisation of populations and the self-management of bodies, especially in illness, involving the making of claims through local and international channels (Richey, 2006; Nguyen, 2010; Whyte, 2012). Patterson (2015:1) defines therapeutic citizenship as ‘biopolitical membership that includes claims and ethical projects that emerge from techniques to control and manage bodies. In some contexts, therapeutic citizenship includes activism and claims-making against local, national, and international power brokers’.

Concerning education, target five of the Muscat agreement on GEA requires that by 2030 ‘all learners acquire knowledge, skills, values and attitudes to establish sustainable and peaceful societies, including through global citizenship education and education for sustainable development’. Target six challenges all governments to ‘ensure that all learners are taught by qualified, professionally trained, healthy, motivated and well-supported teachers’ (UNESCO 2014:3). However, HIV prevalence among teachers is high, and the difficulties of being on ART for Zambian teachers are widespread (Munachaka, 2006; Mweemba et al., 2010). Reports indicate that HIV/AIDS has a strong effect on work (UN Chronicle, 2011), given that the most affected or infected are those who are in the productive years of life in relation to paid and unpaid work.

Therefore, the effect of HIV on personal and national development is that of weakening human resources. Longer-term investment for increased capacity, and the training of more teachers, nurses and other civil servants to replace those who become incapacitated to work effectively through HIV, is a necessity that puts pressure on other development goals (Hargreaves and Glynn, 2002; Bloom, 2005; Whitehead, 2006).

The HIV treatment situation in Zambia is influenced by many factors. Experiences of living on ART differ based on age, gender and locality (CSO, 2014). Treatment for HIV has complex adverse effects on young people and women in Zambia (Avert, 2016). Similarly, professionals such as health workers appear to be negatively affected by HIV trajectories (Bond, 2010). Teacher training, teachers' economic status, their use of effective pedagogy and many other factors have been chronicled extensively by various scholars across disciplines in research on education in developing countries. However, experiences of illness and health conditions among teachers – key actors in implementing the development agendas of many countries in Africa – have received minimal attention. The HIV/AIDS burden in SSA is higher than the resources available to deal with the pandemic effectively (Kharsany et al., 2016), while the number of people living with the virus and on ART in SSA countries such as Zambia remains high (UNAIDS, 2017).

## **1.2 Statement of research problem**

Nowadays, despite the utility of ART, knowledge about the pandemic is constantly changing. This change in Zambia means that HIV is now a chronic illness that seems to be creating a form of therapeutic citizenship (Ngueyn, 2008; Sabina, 2013), which merits significant research. The HIV rates among teachers in SSA, and specifically Zambia, are high, and there are many teachers who are on ART because they were considered a risk group for HIV infection during the 1990s (Kelly, 2000).

Hence, details on how teachers in Zambia understand themselves, and the structures of governance through which they cope with ART-related issues and their chronicity, need to be ascertained. It will be valuable to analyse life on ART through the dual lenses of individual welfare and national socio-economic development. Teachers' well-being, sickness and medication go beyond individuals and their families, affect whole societies and institutions, and have broad national development implications (Bennell and Kwame, 2007). Development depends, among other factors, on health and education (UN, 2012), and the quality and effectiveness of an education system is centred on the health of its teachers. Teachers are key in determining success in meeting the educational goals of any given society (Siameja, 2011:2). Yet for HIV positive teachers, as for other civil servants living with the virus, their situation might be different, as they are expected not only to be effective at their job as professionals, but also to manage

their medicalised lifestyle for a sustained health condition. The medicalisation process does not entail that people living with HIV are medically fine all the time (Williams and Gabe, 2015). This contradiction renders the widespread clinical assumption that one has a ‘normal’ and ‘healthy’ life when on ART problematic in the eyes of some social science researchers (Squire, 2013:67).

Clinical approaches to medicalisation tend to offer a narrow, medical sense of well-being, and overlook the psychosocial and physical concerns of those living with HIV. This study will try to add to the existing literature on health and illness, and to fill the gap with an integrative conceptual approach towards the understanding of illness and health within a framework of therapeutic citizenship in the context of human development in Zambia (UN-ESC, 2002:156).

The effects of chronic conditions such as HIV on individual well-being and national development continue to be less scrutinised, both quantitatively and qualitatively, in Zambia. The repercussions of having medicalised HIV positive teachers in schools, and the prospects for an education system that is driven by HIV-citizenized teachers into development in highly specific ways, remain critically under-researched. It is against this backdrop that we must place the critical question(s) that this study tries to address and the objectives it intends to meet, given in the next section.

### **1.3 Principal research question and study objectives**

The core question that guides the study is: to what extent does therapeutic citizenship status among HIV positive Zambian schoolteachers affect their representations of their lives on ART and shape the possible trajectories of Zambian national development?

The above question is addressed by pursuing the following three objectives:

1. To ascertain what elements of identity underpin HIV therapeutic citizenship.
2. To assess the impact of HIV’s chronicity in the era of ART on teachers’ everyday lives.

3. To evaluate how the governmentalisation of living, health and care for HIV-citizensed teachers is understood and appropriated in this development context.

The following three specific research questions reflect the above objectives, and each of these questions is related and answered in chapters five, six and seven.

1. How do teachers comprehend and cope with HIV and ART medicalisation's influence on their health, relationships, profession and other life goals?
2. What theoretical framework can best explain teachers' own representations of their identities, life courses, and relationships with medical and other structures of governance?
3. What implications does this therapeutic citizenship status have for positive teachers' place in the national development of Zambia?

With these questions and objectives in mind, the sections below give the rationale for this study, and highlight some of the literature and debates around the areas of exploration.

#### **1.4 Significance of study and background literature review**

This section shows the significance of the study, and tries to set out the research around the key issues for the study by giving a survey of relevant literature. Here a general discussion is given of how several scholarly works have shown the synergy between active citizenship, health, education, HIV, teachers and development (Turner, 2000; Sachs, 2002; Chapoto and Jayne, 2005; Risley et al., 2012). But there seem to be very few cross-sector studies of the relationship between HIV, development and education with a specific focus on teachers. This study may provide the entry point for psychosocial and economic intervention strategies in Zambia's education system.

There have been few systematic studies that explore living and workplace conditions for HIV positive teachers. Stakeholders in education are often expected to train a well and highly educated person at the end of the schooling years. However, teachers' quality of life (QoL) has a direct impact on their delivery in schools. Teachers living with

HIV/AIDS have aspirations and motivations, but in most cases have little up-to-date information, especially about their ART adherence and its role in improving their lives. Research on those living with HIV, let alone teachers, has received little attention in Zambia. As observed by Mweemba and colleagues:

In Zambia HIV/AIDS studies have focused on knowledge, counselling, behaviour change, mother-to-child transmission and clinical presentation but there are no published studies which examine the effects of living with HIV/AIDS [for those who are positive] on a person's quality of life and on adherence to antiretroviral drugs. (Mweemba et al., 2010:2)

It is from this premise that there arises the motivation to conduct a study to better understand experiences of adherence to medication, especially for HIV positive teachers. Such a study might propose social, economic, political and culturally sensitive mechanisms that can improve QoL and teaching for HIV positive teachers adhering to ART. This research will provide empirical evidence on how health governance is understood, especially among teachers in Zambia (cf. Kelly and Bain, 2003). According to Mweemba (2008), people living with HIV in Zambia are faced with difficulties in securing a nutritious diet, transport to health centres, and even housing while they try to adhere to ART. These hardships appear to be more likely among HIV-citizened teachers, who are required to execute their duties in schools, which can be somewhat overwhelming.

In this regard, teacher efficiency is curtailed, and this might contradict traditional studies in education research that have shown a positive relationship between national development and teachers' expert roles. A teacher is a facilitator for national development because teachers bear a great obligation to deliver the right kind of skills and behaviours, not only for job creation but also to fill the positions created (Okemakinde et al., 2013; Wanekezi et al., 2011). A responsive or fractured education system is reflective of teachers' status. Adeyera (2011) describes national development as the establishment of a viable and buoyant national economy, the formation of a just egalitarian society, the pursuit of equality and social justice, and the building of an integrated society where the different racial, ethnic, religious and geopolitical identities coalesce to develop a collective sense. Therefore, national development is about how a

nation's resources (including human labour, such as that of teachers) are harnessed for the betterment of the citizenry.

By and large, medical improvements have contributed significantly to the growth of chronicity in world populations, through prevention and treatments that extend life expectancy, and through early disease diagnosis. Larsen (2016) argues that living longer leads to greater vulnerability to accidents and the contraction of diseases that can become chronic in nature. In this vein, Curtin and Lubkin (1995) maintain that chronicity is associated with the irreversible presence, accumulation or latency of disease deficiencies that involve the total human environment for support and self-care, maintenance of function, and prevention of further incapacitation. Without a cure – which is not currently in prospect, except in a very few cases of ‘functional cure’ – the management of HIV/AIDS will forever require long-term governance as a health problem. Chronicity can be perceived positively as the probable increase of an individual's, family's and society's life, or negatively as the failure to recover completely or be cured of a syndrome (Weaver and Mendenhall, 2013). From a health perspective, there is an increasing belief that patients who receive treatment can live perfect lives or return to their ‘normal’ previous roles, even though the client's entire life pattern may offer degrees of increasing incapacitation, pain and deterioration (Pallesen, 2014). This in turn creates a new form of identity from the previous state of health, with wider development implications. Hence, development and health interact in complex and changing ways, and especially through policies. The collective level of influence in the development equation, and the agency of an individual such as a teacher, depends on personal health and capabilities.

However, research on the impact of chronic illnesses has mainly dealt with how specific disease conditions have been hampered by some health measures or the performance of activities of everyday living, rather than being framed within the context of identity. Studies suggest that people undergoing treatment do establish new forms of identity associated with the disease (Larsen, 2016:70; Gois et al., 2012:34). Generally, the central ethical component in any biomedical model is the clinical diagnostic search for abnormalities, without any consideration of the medical implications for social, political and economic normality. As Nye (2003:120) suggests, ‘diagnosis [in medicine] defines the boundary of the normal’, but these boundaries are malleable and subject to socially

constructed interpretations. This implies that medicalisation shapes how individuals and groups make sense of institutionalised practices within socio-political structures. Thus, the process of laying down the boundaries of pathology and norms in bodies and behaviour is a social construction, albeit influenced by medical discourse and determinism (Turner, 2000). The debates and literature are heavily focused on scientific understandings of health and bodies, but not so much work focuses on the interaction of social science domains with medicine and health.

A survey of the literature shows that most of the policy discourse on HIV/AIDS has an intense focus on awareness, prevention, transmission reduction, behavioural pattern alteration and medical presentation. In Zambia, limited scholarly work and research seems to address the issue of adherence to treatment and its relationship to QoL. However, Squire (2013) introduces a discussion of the sociological gap concerning identity formed around HIV medicalisation, dubbing it ‘HIV citizenship’. This is what Nguyen (2008) calls ‘therapeutic citizenship’ in the era of treatment possibility.

Additionally, Squire’s (2010, 2013) work is a testament to how far the HIV crisis is from being over, even in the treatment era. Attention on the disease should now shift towards the complexities of taking medication for those living a positive life. The introduction of antiretroviral (ARV) drugs has helped to increase longevity; the research focus should now shift from quantity (lifespan) to QoL. This implies qualitatively exploring and assessing accounts of identity, governmentality and chronicity as they appear in HIV positive teachers’ interpretations, rather than simply using QoL scales. In the following section, I discuss the epistemological stance and methods to be applied in this research.

### **1.5 Introducing, understanding and contextualising key concepts**

The theoretical basis of this study’s central question is located in Figure 1.1, which depicts the vital interconnected theories. The concepts are sketched in the description, and outlined briefly below (and discussed in detail in chapter three). The foregrounding in this study of these main concepts – identity, governmentality, chronicity and therapeutic citizenship – makes up a significant part of this thesis’s theoretical framing and analytical approach. However, in the first instance it is necessary to consider the context of development and how it is applied here. Development is a multifaceted

process with many components: education and health are important drivers of development, alongside economic and political factors, geopolitics, climate, cultural and historical legacies, and the actions of global organisations (Willi, 2011:26). The level of influence and agency of an individual, such as a teacher, in the development equation depends on personal health and capabilities, which promote economic growth on a societal level via increased productivity coupled with good governance (Hannum and Buchmann, 2006).

In spite of the many meanings of ‘development’, and the extensive criticisms of both discourses and practices of development, the term is employed here to encompass multisectoral, multidimensional, transformative processes which aim to improve people’s lives in social, political and economic terms (Whiteside, 2006). Development in this research is treated not as a concept, but as an area of practice in human progress for improving lives in the context of HIV. Also, the term is utilised in the context of national welfare, which encompasses transformative processes that aim to improve people’s lives from social, political, economic (Fakuda-Parr and Kumar, 2009) and medical perspectives. The understanding of development in this research also draws from Deneulin and Shahani (2009:32) and Summer and Tribe (2000), who describe development in line with long- or short-term processes directed at increased living standards, improved health, favourable welfare, and the achievement of the common good in society. The work of Deneulin and Shahani (2009) emerges from and engages with Sen’s capability approach, which is useful in development discourse but is not part of the focus of this research.

Minimal details exist about how HIV positive teachers cope with ART in Zambia. There is sufficient evidence about the successes of ART, but it appears there are fewer accounts revealing how and why ART achievements are changing knowledge about the HIV pandemic.

There are two underlying issues in the pandemic’s current state. The first is that HIV is now a chronic illness that is potentially creating conditions for new forms of citizenship. The success of HIV treatment is often a representation of well-being in a medical sense and in biological terms. The second is the medicalisation of HIV in relation to biologism and physical health, which has become the basis of normalisation.

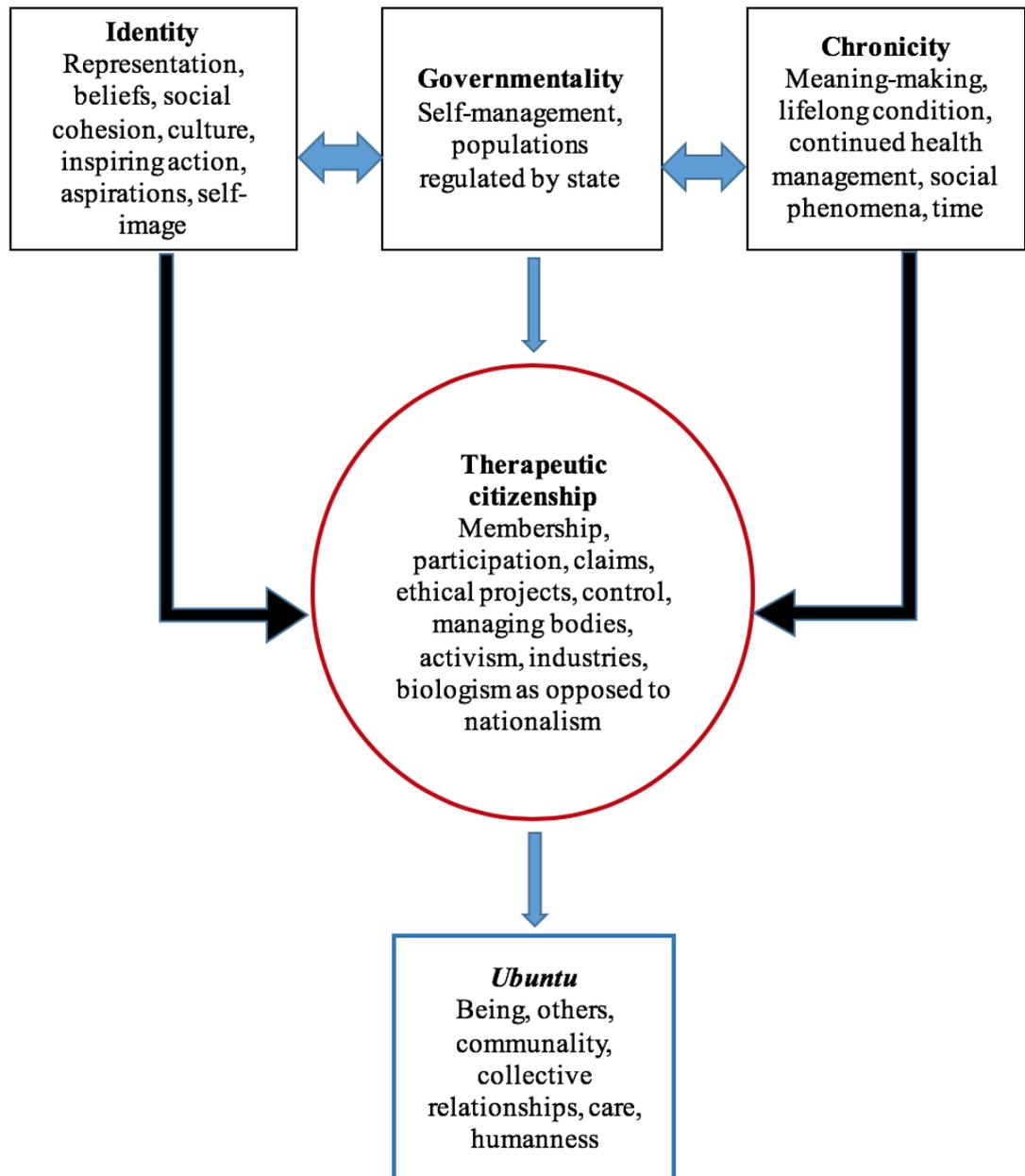
In relation to its key objectives, this study also seeks to interrogate the normalisation process from a social science perspective. In doing so it may provide an entry point for psychosocial and economic intervention strategies that will assist teachers living with HIV and even other chronic conditions within Zambia and the civil service. Additionally, the research makes a significant theoretical contribution.

In Figure 1.1, we see a connected interaction between the notions of identity, governmentality and chronicity, which then all feed into therapeutic citizenship. Each of these concepts is a thread that holds and helps in understanding the characteristics of citizenship from a therapeutic perspective. To avoid the ambiguity associated with the concepts in the diagram, definitions of these terms in the context of this research are first given here, although the terms will be explicated and critiqued to a greater extent and depth in chapter three.

With inspiration from Foucault, the term ‘governmentality’ will be adopted to refer to particular ways in which people manage themselves and are managed in relation to the state. Governmentality is defined as a variety of techniques that encompass socio-political aspects, forms of self-regulation (technologies of the self), and the ‘conduct of conduct’ which produces a form of identity (Foucault, 2008). Governmentality is an important concept in this study, because it explores ways in which people – in this case, teachers – who are ill can be controlled by the state, not only within clinical encounters but also through society’s and their own perceptions, expectations and representations. At the same time, governmentality always involves failures of, contradictions in and resistances to control; these may be forms of governmentality, alternative discourses and practices of management in themselves.

This understanding of governmentality is connected to identity, since it is intimately related in contemporary literature to individualistic notions of the self, and therefore identity, in Western cultures (Murray, 2007).

Figure 1.1: The core concepts of the research and their elements



Identity involves claims, beliefs and processes about and of personal and social cohesion that inspire action. The context of identity in this research is the affirmations of group or individual particularities and desires for belonging, power and recognition (Parker, 2005; Woodward, 2003) that occur alongside chronic illness. Any potential fixed sense of identity, tied to specific states of health, illness and disease, is disrupted by chronic illness, which also produces more fluid notions of the self. Thus, identity is important in this study because it will reveal the extent to which structured roles, symbols and cultures, constructed by the individual and society, are essential in

rendering the self vulnerable, socially and professionally, in conditions of chronic illness.

The relationship between the concepts of identity and chronicity can simply be located in the assumed temporal continuity, maintenance and re-establishment of identity, in accordance with most conventional concepts of it, across long-term health conditions. However, the ways in which individuals with chronic conditions forge new forms of resistance, acceptance and belief about their illness and its treatment also demonstrate the mutability of identity over time (Squire, 2007). The notion of chronicity – a term I am using here to refer to continuing health conditions (Albrecht, 2015) – is thus connected to identity, as it helps in mapping out how individuals make sense of themselves and their relationships with others across such conditions.

Chronicity is defined as ‘an ongoing medical condition with a spectrum of social, economic and behavioural complications that require meaningful and continuous personal and professional involvement’ (Larsen, 2016:5). The concept of chronicity assumes continuing, time-related patterns of illness and uncertainty in health.

Individuals who have experienced chronic illness and are on treatment still face degrees of difficulty and pain (Weaver and Mendenhall, 2013; Whyte, 2012; Yasin et al., 2012), thus putting into question dominant notions of medicalisation and normalisation, and challenging the adequacy of health as a self-project (Rose, 2007) and the techniques of governmentality developed around illnesses such as HIV.

Chronicity in this study is related theoretically to governmentality, which means the objectification and classification of citizens through biomedical forms of conduct based on their biological conditions and medical needs (Nguyen, 2008).

When related to HIV therapeutic citizenship (Nguyen, 2008; Patterson, 2015), the concepts of governmentality, identity and chronicity offer new ways of understanding medical solutions, normalisations, and their limits in the everyday lives of teachers in Zambia who are on ART. Therefore, governmentality in relation to HIV therapeutic citizenship refers to patterns of control over who has citizenly rights – for instance, to treatments and services – and what the conditions are for those rights – for example, adherence, reflectiveness and understanding (Nguyen, 2010). Identity in relation to HIV

therapeutic citizenship refers to people's fluctuating sense of themselves as HIV positive and 'undetectable', and yet also as having many other important intersectional identities. Chronicity in relation to HIV therapeutic citizenship refers to normative ideas of physiological, medical and social progression through diagnosis, successful treatment and acceptance – still accompanied by progression through denial, illness and stigmatisation.

Finally, I want to relate this brief overview of the thesis's starting conceptual framework to African philosophical conceptualisations of *ubuntu*. African nations seem to hold some different, culturally embedded ways of understanding and governing life, disease and health. Drawing from what Ratele (2016:2) calls 'African psychology' and his framing of 'cultural African psychology', I endeavour to use *ubuntu* as a philosophical concept which counterposes life based on communal values to the emphasis on individual ideals espoused in Western contexts (Kapoor, 2008; Letseka, 2012; Albrecht, 2015:611). *Ubuntu* will help this study to argue for or against Afrocentric notions of health and illness in relation to HIV subjectivity, while acknowledging that such notions may be changing and heterogeneous (Ratele, 2004; Squire, 2007:57). The communal ethos of most African societies is built on collective engagement, which currently appears to be under threat in HIV contexts. Through stigma, the HIV epidemic may be dissolving *ubuntu*-produced forms of cohesion and solidarity. Studies have shown that communal livelihoods and traditional settings of African, including Zambian, societies involve people helping each other, following the philosophy of *ubuntu* (Letseka, 2012; Ratele, 2016). However, there appears to be a difference in such *ubuntu*-based discourses and practices when it comes to HIV contexts, because of high levels of uncertainty and fear and little hope, even in this era of ART possibility. Currently, there is nothing in the literature that shows HIV governance reduces *ubuntu*'s influence.

The concept of governmentality is concerned with technologies of the self. The management of a chronic health condition includes technologies of medicalisation, and at times of chronicity and identity these are all directed at individual subjects. But in the African context, *ubuntu* seems to refuse a singular subject, as it emphasises local communities and kinship groups. This refusal appears to be problematic for notions of chronicity, governmentality and identity, which in much contemporary literature put the

self above others – although they may not necessarily operate in this way. In addition, the collective focus of *ubuntu* means that bodies, as they are conventionally known, cannot recover if contextualised in collective rather than singular terms (Foucault, 2008; Shilling, 1993). Bodily experiences are not necessarily containable within concepts of individual subjectivity in relation to HIV (Fassin, 2007).<sup>ii</sup> Thus, in the context of *ubuntu*, individual and collective notions of governmentality, identity, chronicity and the body in the HIV epidemic come into an interesting, complex and productive dialogue.

As can be seen from the above descriptions of each concept, the relationship between the founding concepts of the thesis is complex. The concepts that are examined in this study, as earlier stated, are mainly identity, chronicity, governmentality, therapeutic citizenship, and to some degree notions of *ubuntu*, medicalisation and normalisation. The sophisticated interrelationship of these concepts appears, for example, when chronicity seems to fit with an individual identity based on the self-image acquired through illness, and often through consequent medicalisation and governmentality, which generates a therapeutic citizen who is ‘virally suppressed’, has a ‘long-term condition’, and apart from these factors is just like any other citizen.

When taken together, as we have seen, each of these concepts seems to influence how the others are theorised and used. Moreover, the case of HIV positive individuals who are on therapy appears to extend existing meanings and understandings of citizenship from Nguyen (2008:126), Marshall (1950) and Turner (2000). This reformulation of citizenship is based on the nature and processes of biological and medical aspects of living, related to the state and to a sense of group formation based on individual diagnosis with a condition that requires long-term biomedical intervention. Finally, the unique nature of HIV and its strong politicisation allow substantive connections, as we will see in chapter three, to be drawn among these concepts when applied from biomedical, psychosocial, political and development perspectives.

HIV treatment’s effect on teachers is very complex and cannot be determined by quantitative research alone, as the theoretical considerations above imply. Therefore, this study’s findings and recommendations might benefit those living with and affected

by HIV, especially teachers. It might offer new responses to the study problem outlined above, through qualitative research using semi-structured interviews and differing levels of thematic analysis.

### **1.6 Study setting: data collection and analysis**

This research draws on understandings from participants' own perspectives, rather than simply drawing out the cause-and-effect relations that obtain, for instance, between taking ART and better health. Therefore, the study follows an interpretive design, so as to allow an exploration of social reality not in objective or singular forms, but rather as influenced by participants' experiences and social contexts of understanding, which go beyond singular parts. Through this design, I concentrate on people's own representations and the meanings they give to a phenomenon. Therefore, interviews were an appropriate means of data collection. To grasp people's viewpoints, talking to them is important in social science research, due to the power of expression (language) through which meaning can be presented and decoded (Neuman, 2000).

Semi-structured interviews were employed in the collection of data. This method is consistent with an interpretivist epistemology and a constructionist ontology, as priority focus is placed on the sense of the subjects' or participants' own accounts (Bryman, 2016; Lincoln and Guba, 1985). Subsequently, the data was analysed and seen as a creation of shared experiences and relationships between participants and researcher.

Semi-structured interviews with 41 HIV positive teachers in Zambia aged 25–55 were conducted. This sample size was reached based on the idea that it is the detailed individual accounts that matter in qualitative research, rather than the number of participants. The aim here was not to create statistically significant findings through a large sample size, but to elucidate specific issues which may perhaps allow the transfer, if not the generalisability, of the results to different contexts (Cresswell, 2007:126). Transcripts were processed using NVivo Pro 12, and thematic analysis was employed operating on three levels with elements of discourse analysis.

A three-level thematic analysis of data was designed and used here because thematic analysis is a highly flexible framework (Braun and Clarke, 2006:78). One of the aims of this research is to identify patterns of meaning; as an analytic method, thematic analysis

is the most appropriate for this task: it describes and organises the data set in extensive detail that can capture different issues beyond those focused on in the study objectives; it can address variations of meaning imparted to apparently similar phenomena; and it can take into account forms of representation that themselves generate themes.

Language in HIV research matters, because the normalisation of HIV cannot only be achieved through the use of positive or negative expressions. For example, stigma cannot be eradicated by storying HIV in a way that is devoid of societal difficulties whose realities transcend language.

Often, data patterns in thematic analysis are identified through a bottom-up (inductive) and top-down (deductive) approach (Frith and Gleeson, 2004). I used a combination of inductive and deductive approaches, largely because the themes were determined by the data itself as well as by the theoretical framework explained previously. The integrated conceptual initiative I applied was an attempt to work with existing research, and also to allow the transfer of claims, which will help with the external legitimisation and evaluation of new insights on the topic (Lincoln and Guba, 1985).

## **1.7 Synopsis of thesis chapters**

*Chapter two* provides the context, and traces background and scholarly debates around health, education and development in Africa, especially Zambia. This chapter also reviews the literature on teachers and the HIV situation in Zambia and elsewhere. I show how my application of the concept of development is not just located within the wide landscape of economic understanding. Attention in this research starts with a narrow economic focus and then moves outwards to cover social, political and cultural aspects, as well as situating education and health as either means or ends to development. The chapter shows the progress, problems and prospects of HIV as a treatable illness in SSA, Zambia included. Based on my survey of the literature, I argue in this chapter that HIV has both latent and visible physiological, psychological, social and economic effects on infected and affected individuals, often through policies and institutions operating at national, regional and international levels.

*Chapter three* explores the literature on the central concepts of this study. It sets out the conceptual framework, and places citizenship in an HIV treatment context. The study's dominant concepts emanate from the issues raised across the reviewed texts. The focus

of the chapter is to review notions of identity, chronicity and governmentality by defining, contextualising, critiquing and relating them to the concept of therapeutic citizenship. Identity here is used to refer to how health and disease states relate to socially normalised or excluded social identities (Pallesen, 2014). The theory of chronicity deals with long-term, subjectively experienced medical conditions in everyday life (Benton et al., 2017; Larsen, 2016). Governmentality, as applied here, follows Foucault's conceptualisation, which suggests that the state deploys particular ways of managing people that fit with and reproduce state discourses and practices (Bulley, 2014). Reference is then made to the effects of HIV treatment among teachers in Zambia, to bring this conceptual framework to bear on the empirical concerns of the thesis.

*Chapter four* discusses the methodology that this study employed, the epistemological position of this research, and how and why a qualitative method of enquiry was chosen to achieve the objective of the study, albeit not without some descriptive quantitative sections. Furthermore, the chapter highlights the recruitment procedures that were followed, and considers the ethical issues that are crucial in research involving human subjects. The chapter describes how semi-structured interviews with participants were conducted, and how the analysis was done.

*Chapter five* conveys what the participants in this study make of their chronic health condition as HIV positive teachers. In this chapter, findings are presented using descriptive statistics to relate some demographic patterns to patterns of response, and then presenting a thematic analysis of participants' representations of their own perceptions and everyday experiences in relation to self and others. The findings presented in this chapter demonstrate that many factors shape the self-representations of participants as teachers living on ART and with HIV. These factors include past experiences of illness and present events such as positive and negative interactions with healthcare, and they take in general representations of health and illness; accounts from diagnosis to treatment; reasons for commencing ART; long-term and short-term effects of HIV treatment; management of ART effects; therapeutic hope and uncertainties; disclosure, acceptance and stigma; interactions with healthcare personnel; personal, microsocial and meso-institutional forms of support; and the nature of interactions within school communities while one is living on ART.

*Chapter six* demonstrates three key higher-level discursive themes that emanate from the results – that is, three larger meso themes that cut across the themes described in chapter five and are identified in part by examining how participants’ representations connect to power relations. These larger themes are discussed and analysed separately, with a focus on the data that generates each of them. Then it is highlighted how the findings from chapter five cluster in the three emerging themes. This higher-level thematic analysis – working on the initial micro themes within the results, and paying attention to the discursive power relations operating within and across themes – reveals three broad meso themes: biomedicine, temporality and sociality. Micro themes related to biomedicine are made particularly prominent by a broader meso theme of biomedical power, in which the body appears to be governed through medicalisation, but bodily requirements remain difficult to negotiate within working lives. This mid-level theme is related to, but makes more specific, the thesis’s initial theoretical framing around governmentality. The meso theme of temporality is associated with the normalisation in the data of living with HIV over time, including across professional careers, and it develops the thesis’s early theoretical interest in chronicity. The meso theme of sociality demonstrates how being on ART is socially constructed in relationships with family, friends, colleagues and students; this theme builds on the earlier thesis framing around identity. This research finds that although HIV citizenship can be associated with the (de)professionalisation of life for the participants, it has also enhanced state-citizen relations due to free ART, and it has increased teachers’ pride in what their students achieve, making their HIV less relevant and perhaps less stigmatising. All three meso themes point to how participants’ accounts of therapeutic citizenship are presented as their own.

*Chapter seven* situates the data, and my prior analyses in chapters five and six, in the context of the notion of therapeutic citizenship and its implications for national development, decoloniality and *ubuntu*. Using a macro-analysis which looks at discursive themes – again related to relations of power – across chapters five and six, the chapter shows the dissonances and continuities of being an HIV citizen in the contemporary treatment era for *Zambian* teachers. I emphasise in this chapter that in this ‘muddled treatment’ era, sociality, biomedicine and temporality around this chronic condition and its highly successful treatment still appear challenging. Consequently,

being HIV-citizenized and on ART are conditions that fall out of the ‘normal’ within sociological and political spaces of human interaction, even for many well-educated and relatively well-resourced people living with HIV in Zambia – for instance, teachers I interviewed who continued to use the phrase ‘life changes when you are on ART’. This citizenship comes about through social identity constructions that arise from being ‘medically reliant’, and from the continuous practices of daily medication, as well as from the normalised ‘career’ temporality of living with HIV and ART as a person and a teacher, and from the specific social relations that teachers who are HIV positive and on ART have with others around them. HIV appears to have advanced self-, communal and professional governance, and to have created an HIV ‘republic’ defined by a complex or ‘muddled’ treatment citizen (or HIV citizen) condition. My participants valued this ‘muddled’ HIV citizenship both positively – particularly when they presented it as part of a national project of commitment to (treating) HIV positive citizens and enabling them to pursue their professional lives – and negatively, particularly when they had problems themselves with ART or stigma.

The data in chapter six showed that management of a chronic health condition such as HIV includes social, biomedical and temporal technologies of the self. However, in chapter seven I analyse how in the African context the data also fits with the concept of *ubuntu*, which seems to refuse a singular subject, as it emphasises local communities and kinship groups in dealing with illnesses and other life challenges that bring humanness into the picture. As many Zambian citizens, including important population groups such as teachers, become HIV treatment citizens, there are wider and long-term national development implications for Zambia’s capacity – its human, material and medical resources and their sustainability – that arise from the possibility of taking an approach to HIV citizenship founded in *ubuntu*, which this chapter explores. In addition to general medical and social difficulties, problems with achievement-oriented assessments of teachers’ work create extra pressure on their health condition, which makes HIV citizenship a fraught status. The chapter also shows the connections between representations of HIV ownership and wider positive and negative national development implications.

*Chapter eight* summarises the research’s key findings, reveals some limitations of this study, and reflects on how this study contributes to social science understandings of

HIV, as well as on areas for further research. The chapter summarises the analysis by emphasising that being HIV positive and on ART in Zambia can create a specific form of existence which is referred to in the thesis as therapeutic citizenship. The chapter also recapitulates the data in chapter seven about the discourse of a republic of HIV-citizenised persons, which is not about those persons being positive, treated or even successfully treated; it is about a medical and social ‘treatment’ of the condition that puts people with HIV in a ‘muddled’ place as ill and/or healthy.

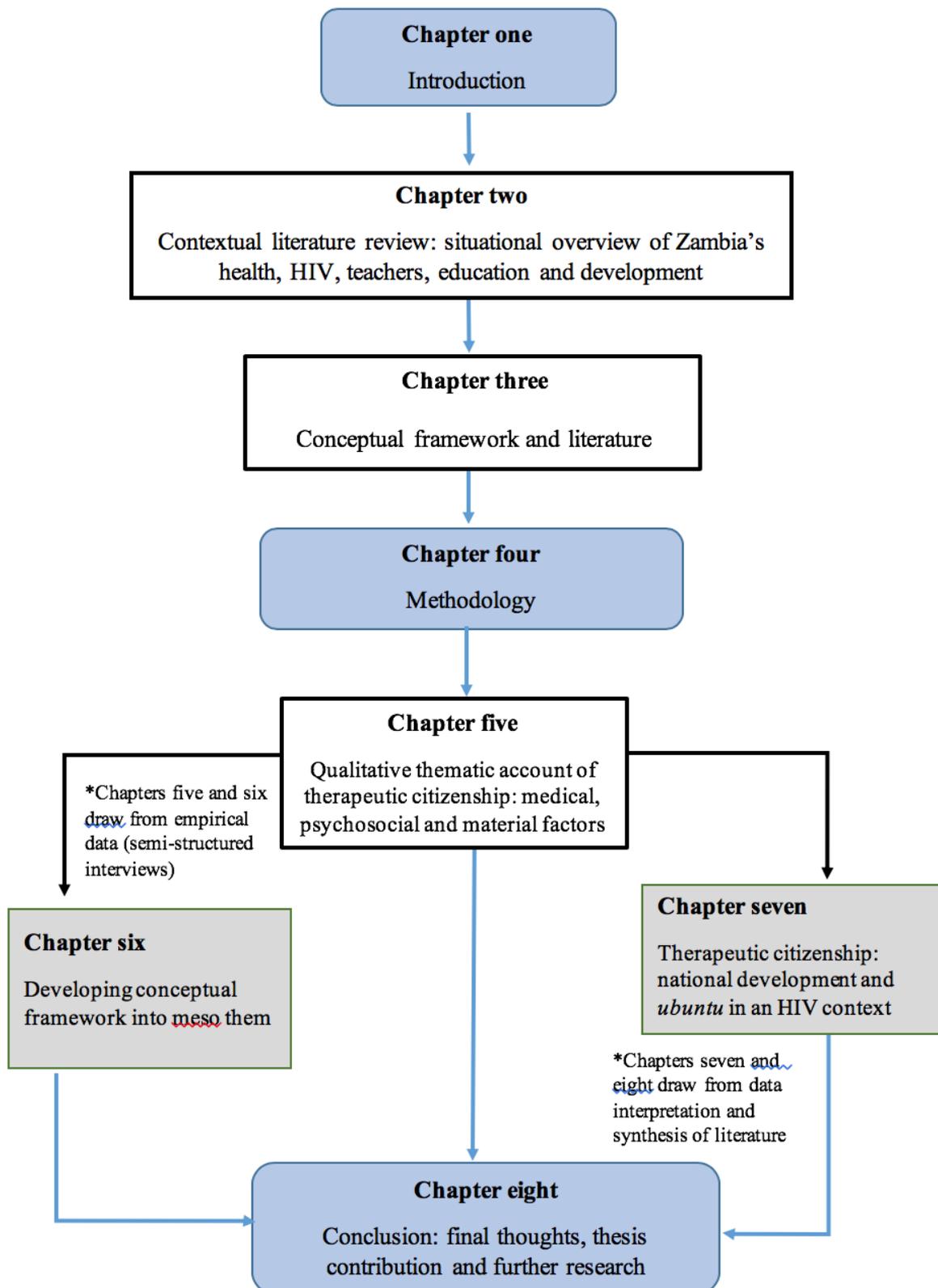
The chapter further highlights the empirical and theoretical contribution of the thesis by demonstrating how things are going in the Zambian HIV epidemic for a particular and important population group, what challenges and successes are reported by them, and what their HIV citizenship currently looks like. The findings have both macro and micro implications for individual and collective action, which perhaps can positively or negatively influence national development trajectories for a low-income country.

## **1.8 Chapter summary**

This chapter has set the scene for the thesis by providing some background information around the global, regional and national HIV situation and treatment. The chapter has described the research problem within a broader context but based on Zambian questions about HIV citizenship. The main research question has been stated, and the three key objectives through which the question will be addressed have also been outlined. The significance of the study has been demonstrated through a brief literature review. The conceptual framework of the study has been introduced by describing identity, governmentality and chronicity, as well as *ubuntu*, through which therapeutic citizenship is understood.

The setting of this research and methodological issues have been briefly explained in this introductory chapter, and a synopsis of the thesis has been given. Each of the eight chapters’ aims, and the core propositions for how these aims will be addressed, has been itemised. The next chapter is a literature review that provides the context for the HIV situation in Zambia and beyond.

Figure 1.2: Thesis structure



## Chapter two

### Literature review: context and situation of HIV in Zambia and beyond

#### 2.0 Introduction

There has been progress in HIV treatment efforts around the world, in spite of challenges. People living with HIV in underdeveloped nations have benefited most from generic drugs and scale-up projects. Yet in spite of national, regional and global programmes in the fight against the pandemic, there are ongoing debates regarding how HIV has decreased life expectancy, deepened poverty, decreased socio-economic development, and fractured education and health systems (UNAIDS, 2016; Whyte, 2015). The aim of this chapter is to give a context for the HIV situation around the world, and specifically in Zambia. The chapter reviews literature on issues around teachers, development and health in Zambia and elsewhere.

The chapter has four main sections. The first section gives a generic account of the health and HIV situation in Zambia in relation to teachers. The second discusses the idea of health in relation to HIV. In the third section, the association between health, development and education is determined. The fourth part generally theorises the dynamics of teachers' health and their role in education and national development. In the passages that follow, I give a background on the key topics addressed in this chapter.

It is against the backdrop given in chapter one that this section of my thesis aims to discuss issues around HIV and teachers' medicalisation in the Zambian context, setting a basis for the conceptual discussions of identity, governmentality, chronicity and *ubuntu* in the next chapter. This chapter will ascertain the dynamics of health and development, and will consider the role of HIV-infected and affected teachers in this treatment era. In this era of treatment, perceptions of the HIV pandemic seem to be split between seeing it as a disappearing tragedy and seeing it as a treatable illness with latent psychological, social and economic effects (Lichtenstein, 2015:858). The latter proposition and experiences of managing HIV are part of the central argument in this thesis, and they are supported by the three fundamental concepts stated above. When critically synthesised (as will be seen in chapter three), the concepts briefly

contextualised above offer new ways of understanding medical solutions, ‘normalcy’ and their limits in the everyday lives of teachers who are on ART.

## **2.1 Background**

HIV is an infection that weakens the defence system of the human body, and once acquired it leads to life-threatening problems or death. However, treatment with ARV drugs can slow the development of HIV into AIDS, and can reduce chances of virus transmission. There has been immense investment in the HIV/AIDS epidemic. Yet research on the disease shows that it seems to be persisting, since its impact is still felt in virtually all spheres of life, including education (Whiteside, 2006). About 78 million people have been infected since the time the first case was documented, and an estimated death toll of 35 million people worldwide has been linked to AIDS (UNAIDS, 2016). The large majority of those living with and affected by HIV are poor, and most poor people who are HIV positive are in developing countries in southern and eastern Africa, where over 19.6 million people are living with HIV, with about 800,000 new infections yearly. Over 10.3 million people are receiving ART, and over 380,000 annual deaths are related to AIDS (UNAIDS, 2018; UNDP, 2016).

HIV/AIDS is on the global development agenda. In 2015, a strategic plan for 2016–2021 was released by UNAIDS. In line with the SDGs, it calls for a strengthened global response in HIV prevention, diagnosis and treatment (UNAIDS, 2015). In parallel, country-based actions aim to integrate HIV testing and treatment services into a range of care in order to reach the UNAIDS 90-90-90 targets by 2020. These targets aim to ensure that 90% of all people living with HIV will identify their status, 90% of those who know they are HIV positive will have access to treatment, and 90% of those on ART will have low viral loads. While making the disease a chronic condition, the development and use of effective HIV drugs is reversing the history of an epidemic that began with panic, affliction and death. ARV drugs are now enabling HIV positive individuals to live long and ‘healthy’ lives (Whyte, 2014).

Zambia has its own, inadequately chronicled history of the impact of chronic illnesses, especially HIV, on individual well-being and national development. The first case of HIV/AIDS in Zambia was reported in 1984. Ever since, the country has been one of many SSA nations on which the pandemic has negatively impacted. In 2004, the

government of Zambia declared HIV/AIDS a national emergency and committed itself to providing free ARV treatment for at least 100,000 people by the close of 2005 (Mweemba et al., 2010).

Currently, it is estimated that over 1.1 million people are living with HIV/AIDS in Zambia. With the prevalence rate standing at 11.5% and 48,000 new infections annually, 76% adults are on ART, and there are slightly over 20,000 AIDS-related deaths yearly (UNAIDS, 2018). The Ministry of Health in Zambia has recently increased access to treatment by creating 68 new ART sites, in addition to supplying drugs to all existing ART sites nationwide. Assessment laboratories for monitoring HIV positive patients are present in almost all provincial hospitals and district and community clinics. These figures speak to how the Zambian population is slowly, if not yet fully, being medicalised.

## **2.2     Zambian teachers: progress, problems and prospects of ART**

The situation facing HIV positive teachers across the continent perhaps represents a microcosm of the difficulties facing African states more broadly. Whyte (2015) argues that in the neoliberal era, a series of ‘para-states’ has emerged across SSA, with Zambia a case in point. For instance, Zambian teachers are on government payroll, but many of them who are HIV positive have complex treatment and resource needs that are largely met by donor provision of free ART drugs, not by the state. Compared with the pre-treatment era, the number of people, teachers included, dying from HIV/AIDS related illnesses has drastically reduced (from 66,272 in 2003 to around 21,000 in 2016) due to early diagnosis and free provision of ART in Zambia (CSO/MoH, 2015; NAC, 2009; UNAIDS, 2017). These figures speak to how the Zambian population is slowly being moved towards the 90-90-90 goals (UNAIDS, 2017) of near-universal and effective HIV testing and treatment – which also has preventative effects, since effective treatment correlates with a lack of transmissibility, or as UNAIDS now puts it, undetectable = untransmissible (U=U) (The Lancet, 2017). There is a growing body of large-scale epidemiological studies (Maartens et al., 2014; Simon et al., 2006) which have shown that treatment works as prevention. This increasing emphasis on medical solutions may indicate the medicalisation of HIV in Zambia, which would in turn have implications for national development.

The clinical claim that one has a ‘normal’ and ‘healthy’ life when on ART is questioned here, particularly in relation to psychosocial issues. The notion of normalcy as perceived in medical spheres seems to be problematic in the eyes of many social science researchers (Kippax, 2010; Squire, 2013:67). The concerns around the medicalisation of HIV, and contemporary neglect of social well-being broadly understood (Harper, 2009), indicate that the epidemic cannot and should not be ‘normalised’ by clinical medical approaches. Whitside (2006), Squire (2010, 2013), Whyte (2014) and Patterson (2015) all testify to how deep and far-reaching the crisis of HIV is, and how far it is from being over, even in the treatment era. The discourse of HIV, as with other conditions such as cancer and tuberculosis, is slowly shifting from that of a fatal illness towards that of a chronic illness accompanied by the complexities of taking lifelong medication and living a positive life. The need to shift from a clinical and epidemiological focus to exploring more social-scientific ways of understanding the impact of disease is born from the idea that illnesses are not only something people acquire and die from, but also something that individuals such as teachers live with in the long term.

In Africa, including Zambia, teachers work under hard economic conditions with very low pay. Teachers may have some cash income, but they are not as wealthy as other professionals. This is the case in spite of the crucial role they play in shaping and teaching pupils who become future human resources in various fields (Abdukareem, 2001; Bennell and Kwame, 2007; Buckler, 2016). Many HIV positive teachers lead relatively healthy lives, and yet medical difficulties remain alongside economic constraints and social stigma. The interaction between the duties and difficulties of teaching as a profession, unfavourable socio-economic conditions, navigation through this chronic condition (Sabina, 2013), and the effects of ART medication makes teachers’ lives, in and outside school, an important subject that needs to be studied. The difficulties faced by teachers on ART in Zambia concern uncertainties about their health and self, public stigma within school communities, and limited or no access to social and medical support networks beyond the medicalised ‘normalcy’ provided by ART.

With regard to teachers, their role in the development process in Zambia has some methodological significance. As mentioned earlier, teachers are the target population for this study because they are the largest public workforce in the country. They are socially situated within the middle class, yet they are in a precarious position (they often get

paid little, late or nothing, and may receive little training), and are in a lower income group with a basic livelihood through their salary. Interest in teachers as participants also draws from the growing trend of biomedicalisation around HIV/AIDS, which means the epidemic is increasingly being normalised through medication (Kaufman et al., 2004) and outside social determinants, and across different socio-economic characteristics of any given population. The choice of teachers is therefore driven by their middle-class status, the role they play in national development as the largest public workforce, and the devastating HIV situation for this sector prior to ART access in SSA nations.

A teacher is a significant facilitator for national development. Various scholars show that teaching as a profession positions individuals as agents of development because of their role in imparting knowledge and crafting skills in learners (Buckler, 2016; Wanekezi et al., 2011; Okemakinde et al., 2013). Therefore, the pedagogical approaches that teachers use in the teaching process – such as participatory learning, lectures, debate, role play, group work, questions and answers – are vital in increasing attainment levels, and enable learners to develop important skills for life after school (Capel et al., 2016; Farrant, 1980). To achieve such learning outcomes, education systems thrive when classroom teachers are motivated and efficient (Cohen, 2009).

What does the process of HIV ‘underdeveloping’ public services look like? There have been few systematic studies that explore how the processes work within particular sectors, especially for those affected by HIV/AIDS themselves. In the pre-treatment era, challenges relating to HIV, as well as the number of teachers affected, diminished the quality of Zambia’s education system, owing to both a shortage of teachers and long-serving teachers with HIV who lost health and capacity even if they were still teaching (Kelly, 2000; Siameja, 2011:89). The quality of education in rural areas appeared especially compromised because few teachers, particularly those who were HIV positive and needed treatment, were willing to be stationed in remote schools with no access to transport or good health facilities. Some of these difficulties were exacerbated by lack of choice among teachers regarding the location of their deployment.

From the above we can see the complex interaction of the private and public in illness and health. The effects of health and illness may be better understood from individuals

as members of a much larger social setting and profession, such as teaching. In the three sections that follow, Zambia's health, development, teachers and HIV narrative build on the above themes, discussed by way of a literature review of studies and conceptual materials – starting with health, which is contextualised as an important aspect that determines the wealth of individuals and nations, and is covered in relation to HIV and bearing in mind teachers in Zambia. Various scholars relate the treatment of chronic mental or physical health conditions to the medicalisation of bodies (Tucker and Goodings, 2018; Pallesen, 2014), a process which makes the body and its capabilities central in understanding biomedical experiences of the world. The section that follows highlights the relationship between health and national development in the context of HIV medication.

### **2.3 Connections between health and development in the HIV context**

The WHO describes health as a state of complete physical, mental and social well-being and not merely the absence of disease (Conference, 2002). Hence, any discussions on health should start with and be related to the body (Whyte et al., 2014:224; Shilling, 1993), an important part of a person's self in terms of identity perception and physiological abilities (Fassin, 2007; Pallesen, 2014). It is equally significant both to those who have never experienced any disruptions in their capacities and to those who have undergone physical and psychological changes, for instance due to an ailment. There is a tendency to describe the governing of health and illness from a macro medical point of view. For example, studies such as Annandale (2015) and Flowers et al. (2012) acknowledge that health is part of the microsocioal problem. For instance, behaviours of not having concurrent sexual partners, as identified by McDonald et al. (2016), are a form of self-management shaped by medical and social health issues for those on ART and living with HIV. In a study by Young et al. (2019), the social aspect of ART was tied to some participants' descriptions of their HIV treatment as toxic to the body, with social implications. The social and medical aspects of the above studies are useful in this research, even though the latter focuses on heterosexual participants – a different sample for example from Young and colleagues' cohort of gay participants. Most major health crises are confronted from a global, regional and continental perspective (Benatar et al., 2011). More specifically, the HIV situation and development discourse in Africa suggests that the disease makes people vulnerable to poverty, and that material lack is exacerbated by the pandemic, even in the treatment era (Murray et

al., 2013). Marmot (2015) maintains that the relationship between health and socio-economic development depends on people's work and well-being. The conceptualisation of health factors within development discourse needs to include the range of economic, social, physical and environmental issues. In this view, people living a healthy and normal life with HIV, usually though not always on ART, as well as those not on ART who are experiencing difficulties, should be conceptualised as part of development processes (Whyte, 2015).

As stated in chapter one, this research is located within the larger landscape of development. The meta-analysis of the development literature by Jolly (2003) provides a wider entry into the shifting trajectories of the meaning of development since the 1950s. The focus on human welfare in 1980s debates on development coincided with the outbreak of the HIV epidemic, especially in Africa (Summer and Tribe, 2008; Barnett and Blaikie, 1992). Additionally, shifts in the understanding of development, from an economic growth focus on social and economic advancements only to encompassing the multidimensionality of development, led to situating education and health as key areas in the framing of not only human but national development (Fukuda-Parr and Kumar, 2009; Mehrotra and Jolly, 2000).

Advances in medical technology have improved the capacity to restore bodies and sustain health for people living with chronic conditions. But the impact of medicalisation is largely questioned on the basis of normalising bodies reliant on medicines. Studies by Shilling (1993) and Foucault (2008) problematise the body and show it as often the first point of focus in any attempt to gain health through biomedical interventions. Contrarily, Morris et al. (2012) argue that the body is – besides physiological and psychological aspects – a construct of social forces when one is living with or recovering from a long-term health condition. Hence, a common link between the social and medical constructions of health is explored in this research.

The HIV testing and treatment situation is changing. WHO (2015) reports indicate that the early initiation of ART has medical benefits and reduces HIV transmission. Bigna et al. (2016) state that ART must be prescribed for all HIV positive individuals regardless of their CD4 cell count and age. The use of CD4 cells (also referred to as CD4+ T cells), which resist the virus, is considered normal when between 500 and 1500 (WHO,

2013). However, in most African nations, Zambia included, it appears the application of a CD4 count (how well the immune system is functioning) below 200 is in many cases still the basis of eligibility for ART initiation (Amanyire, 2016). Although the mandatory testing policy introduced in 2017 by the Zambian government is commended, achieving the 90-90-90 goals appears to be a long and difficult route for Zambia. The advancements in ART, and also the availability of information and government policies in Zambia, are leading to early treatment upon a positive HIV test (Mwanza, 2015).

Health is centrally determined by location and gender, among other things. For example, Hegdahl et al. (2016) have indicated that where an individual lives has an effect on the state of their health, as access to care and treatment facilities as well as other material resources is dependent upon proximity or locality. Squire (2007), in her study on HIV positive women in South Africa, found that rural participants faced challenges relating to distances between hospitals and homes. Also, the work of Kerry and Thom (2009) identifies rural populations as particularly vulnerable, with poor health outcomes due to limited health facilities. In a similar vein, literature covering the effects of HIV shows that location has a bearing on healthcare and services. Studies such as Flowers (2010) and Fylkesnes et al. (2013) suggest that experiences of ART are harder for rural than urban dwellers due to medical service access and availability issues that affect people of all genders.

The link between health and gender is that the male-female divide can be widened in chronic illness due to underdevelopment and resource constraints which differently affect men and women. According to Kilburn et al. (2018), cash transfers help young women in South Africa by reducing risk behaviours, and also improve female psychosocial well-being in poor families. Although the focus of this study is not on HIV positive women, it exemplifies the fact that resource constraints based on gender can affect general health, behaviour and life management. Murray et al. (2013) show that there are significant differences between men and women regarding the timing of HIV diagnosis, and that females often get tested much earlier after infection than males. In a survey of 18 countries in SSA, Hegdahl et al. (2016) found that the ratio of female HIV survivors was higher than that of men, as most males died from HIV and had a high infection rate compared to women in the long term. The study concluded that females

faced more social and economic hardship associated with living with HIV than males in Africa. Although this study is revealing, the methods used differ from this research, as less detailed information from statistics does not provide clear reasons for these gendered differences in HIV. This research attempts to fill this gap by using qualitative approaches to understand differences in health experiences based on gender, as perceived by people that are living with HIV themselves.

Therefore, a relationship appears to exist between gender inequalities in health and living with HIV. Amin (2015) found that well-being differences between men and women shaped not only their reproductive health but also adherence to ART, and made them vulnerable to resource insecurities. The study also showed that women were more likely to be blamed for HIV infection in a relationship than men. Although this paper explored pathways for addressing challenges women faced in living with HIV, it did not adequately show the role of men in interventions aimed at reducing gendered inequalities. Similarly, a number of authors have reported trends in gender and HIV which demonstrate negative social experiences for women living with HIV (Camlin et al., 2018; Colvin, 2019; Russell, 2019). These studies show the systemic effects of HIV treatment on gender, but do not explicitly examine cultural elements in patriarchal societies. This will be a key contribution of this research, with empirical evidence coming from Zambia. Also among gender issues in ART research is the aspect of living with HIV, which seems to create problems with intimacy, as examined by Squire (2003) in a longitudinal study of HIV positive women's stories about finding love in the UK. The social context of hardships in romance and reproductive (im)possibilities highlighted by Squire is instructive for this re-exploration of sexuality here, even though her study was not done in Africa.

Sexuality practices and information among HIV positive individuals in a country such as Zambia seem to focus mainly on behavioural change and less on ART as prevention. Studies (Young et al., 2019; Grace et al., 2015; Persson, 2016) on sexuality show that recent HIV diagnosis means a drop in or poor sex life, and that living on ART cannot recast HIV as a non-infectious disease within couples, even though treatment is regarded as prevention. These authors associate biomedical practices with possibilities of not transmitting HIV, but also call for social and medical vigilance. Although

revealing, these studies were done abroad, and are not about the sexual or reproductive health experiences of people on ART in Zambia, an issue covered by this research.

Health in HIV management is associated with the politics and sociocultural generalities of bodies that have a chronic illness, making ART in HIV treatment both a private and a public issue (Fassin, 2007; William, 2015). Several studies (Belgrave and Charmaz, 2015; Mazanderani et al., 2012; Nixon et al., 2017) have revealed that coping with the medical demands of a long-term condition is determined by the need for knowledge, self-care, and medical, material and informational resources. But lack of access to nutritious food compromises the already weak immune system, with high chances of drug-resistant mutations and recurring HIV-related illnesses (Stillwaggon, 2001). Levels of managing chronic conditions can depend on care and forms of relations between health workers and clients. Interactions between health service providers and users can be positive and/or negative. Numerous studies (Dawson-Rose et al., 2016; Stutterheim et al., 2017; Thompson et al., 2015) have found that the interaction between HIV positive individuals, who may also be substance users, and health personnel is positive, for example if confidentiality is assured; experiences are negative, for instance, when delays are involved in being attended to at the hospital. In contrast, studies by Stringer et al. (2016), Stutterheim et al. (2014) and Kennedy et al. (2017) maintain that lack of privacy, harassment, and poorly trained volunteers who obstruct data or lose records for clients are considered parts of negative experience by users. However, all these studies were done in developed countries where healthcare systems may differ from that of Zambia, a low-income country.

The Zambian economy is driven by a combination of sectors: agriculture, mining, construction and manufacturing. Each of these sectors contributes a significant percentage towards the gross domestic product of the country (CSO, 2014). Nonetheless, the country is heavily dependent on the mining and agriculture sectors. In the early 1990s, the country embarked on structural adjustments programmes which were aimed at reviving a stagnating economy. These programmes had negative effects on key sectors including education and health, such as reduced government subsidies on some public services (ZDHS, 2015). These negative effects of structural adjustment on key sectors that are also highly salient for this study were exacerbated by the HIV pandemic, which continues to have a strong impact on education and health. Studies

(Bond, 2010; CSO, 2014; Siameja, 2011) have suggested the likely effects of the HIV pandemic on the Zambian health sector, as argued earlier in the chapter. Other studies (Whiteside, 2014; UNESCO, 2012; Bennell and Kwame, 2007) have demonstrated the powerful effects of HIV on the education sector. The effects of these factors remain high in rural schools. Teachers' preference for deployment in urban schools deprives rural schools of newly and better-qualified teachers, which disadvantages pupils and compromises education quality for the nation (Siameja, 2011:89). In the aftermath of the nation's pre-treatment loss of teacher resources, this continued urban skewing of such resources means the loss is particularly hard to remedy in rural situations.

Global inequalities have deepened within the treatment era. The WHO's (2015) social determinants of the health of populations seem to be shaped by systemic interactions between different dimensions of power (such as states and constitutions) and productive capacity (markets). The persistence of the processes that undermine such institutions and public provisions, particularly through globalisation's neoliberal economic policies and governance, tends to deepen the already extreme inequalities of income and wealth, resulting in high global health inequalities, especially for chronic conditions (Kapoor, 2008). Further evidence on the need for self-management of chronic conditions such as HIV in low-income countries can be found in studies relating to economic and social variables in chronic lifelong conditions (Olmen et al., 2011; Uebelacke et al., 2015). What these studies do not explicitly show is the increasing caseloads of chronic conditions associated with the deployment of both preventative and therapeutic management techniques for living on ART by individuals and the state.

The highest number of people living with HIV in the world is in SSA (UNAIDS, 2018). Moreover, Kesby et al. (2003) state that factors such as high levels of poverty's effects on the fight against HIV in SSA are partly influenced by global inequalities in healthcare, and controversies around the affordable provision of pharmaceuticals and health treatment by the richer nations of the world (MacDonald, 2005). For instance, the increase in HIV-related health cases in the UK and Europe has in part been attributed to African and Caribbean immigrants seeking affordable and good health services (Hamers and Downs, 2004).

In Zambia, the HIV/AIDS-related policy programmes in the era of treatment have made

it possible but sometimes difficult for individuals to work and support families (Mweemba, 2010). Because incomes decrease due to medical needs among those affected, they are unlikely to have improved lives (Barnett and Whiteside, 2002). Businesses in general are affected by HIV/AIDS due to low productivity facilitated by medical appointment demands, and the recruitment of unskilled or semi-skilled employees who then increase the costs of training to avoid poor-quality performance of their work (Ellis, 2007). Attention has often been on national development and how it can promote good health. Mamort (2015) argues that health can often serve as a platform for progress in other areas, given a suitable policy and political environment. In addition, improvements as well as crises in a person's and a population's health often have the greatest effects on socio-economically vulnerable groups, such as teachers, who have low wages and are under public scrutiny in society (Brentlinger, 2018). Healthy individuals also contribute to the good health of those around them, because they do not become disease burdens, but instead look after others (Marmot, 2012; Sachs, 2002).

The extraordinary nature of the HIV/AIDS pandemic lies in its being both an emergency and a long-term development issue (UNAIDS, 2015). There are various ways in which HIV/AIDS hinders human capital growth and consequently stagnates development. Through the death or poor health of millions of adults, the supply of human resources – for instance, teachers – for service delivery increases the difficulty of having enough qualified persons in education. The loss of a large share of the skilled workforce may reduce the social returns to skill among educated people who survive. The loss of physical vigour may reduce the ability of skilled workers to contribute to overall economic production, insofar as physical and human capital are complementary (Cosgrove and Curtis, 2018).

Veenstra and Whiteside (2005) predict that the repercussions of HIV/AIDS, which may include development aspects, will keep moving from one generation to another, entailing wide-ranging and inevitable social and identity transformations, even within this treatment era. More generally, Mtika (2003) contends that current and future biological, social and economic reproduction depends greatly on the health status of citizens, especially the working-class population. Since AIDS mostly strikes young adults, it is therefore striking the core of the resource flow system in subsistence

economies in the global South such as Zambia, where children and the elderly are heavily dependent on the family's productive middle generation (Barnett and Clement, 2005). By striking the middle generation, the HIV/AIDS epidemic thus disrupts and erodes the intergenerational sequence of support systems, and creates more socio-economic routes of dependency for those living on ART and affected by HIV.

With the above in mind, there are many ways in which health and development correlate. Health and education are essential aspects of both individual prosperity and national development (Marmot, 2015). Despite the successes of ART, knowledge and perceptions about the HIV/AIDS pandemic are continuously changing, especially among significant populations of professionals such as teachers. Since the body is a biological unit, in biomedicine it must be given attention. The person occupying the body should be the first to understand, care for, train, treat and optimise it. It is also the responsibility of medical practitioners, other professionals and the state to care for this body. In the next section, the relationship between education, development and HIV is revealed.

#### **2.4 The relationship between education, development and HIV**

By late 2005, owing to the effects of the AIDS pandemic in Zambia's education system and the difficulties of accessing treatment in Africa, the government of Zambia had made it clear that it would increase treatment access to 75% by the end of 2010 (NAC, 2009). In the early 2000s, the struggle was no longer against new infections. The focus by government and other stakeholders in the fight against HIV was on increasing the provision of ART for those diagnosed as positive, especially teachers and health workers, who were dying in numbers due to a lack of knowledge about care and the tools to enforce universal precaution protocols for handling overwhelming local hospital admissions of HIV patients (Bond, 2010; CSO, 2014; Siameja, 2011).

As earlier noted, teachers represent the largest portion of the public-sector workforce in Zambia, and any potential disruptive effects of HIV treatment on their duties can be very complex to determine by quantitative estimates. Although the downside effects of HIV on the economic front are vast, the establishment of enhanced ART for teachers is largely cost-saving in Zambia (Risley, 2012:12). According to Badcock et al. (2002), teachers in countries such as Zambia, Tanzania, Malawi and Kenya had a very high

HIV/AIDS mortality rate in comparison with other professionals in SSA in the 1990s, due to high infection rates and lack of effective treatment. A survey of literature indicates that there are no recent studies that focus on HIV, teachers and education in Zambia.

Before the treatment period, the impact of HIV on education in Zambia was also seen in perpetual illness-related absenteeism, increased school dropouts, and funerals. Abdu et al. (2016) state that the number HIV deaths among teachers in Zambia was equivalent to those graduating from teacher training colleges in each given year. However, by the end of 2012, the provision of ART had reduced teacher absenteeism in Zambian schools by 40%, and teachers' deaths by 38% internationally (Risley et al., 2012). In the same study by Risley and colleagues, it was also found that most teachers who were on ART lived in SSA. As of 2010, Zambia had over 12,000 teachers (out of approximately 70,000) living on ART with less medical and social support (Ministry of Education, 2014). This fraction was growing and is likely to be currently much higher. Mfinanga et al. (2015) found that in period of a year, and out of 1001 participants in a clinic community support group, 134 had died. In contrast, 180 out of 998 clients had died under ordinary care but outside the clinic group. These authors conclude that mortality was lower with ART in a clinic support group set-up than in a regular care group. Although not on teachers, the study evidenced prolonged and good physical health due to ART, and the importance of hospital peer support groups.

The education workforce has been weakened by the demands of treating HIV/AIDS in most parts of SSA, which is initiating a vicious spiral whereby poor health in teachers hinders the education of children or learners in the school system (Vogl, 2012). Consequently, any changes in the health sector can have either positive or negative effects on education system outcomes such as the achievement rates of learners (Bloom, 2014). This shows an association between education and health, since the health status of a teacher can affect the way they teach and may hinder effective learning. The HIV/AIDS epidemic, before the treatment era, was linked to high dropout rates, low enrolment and poor completion rates among orphans due to the untimely deaths of parents or guardians. Today, with the advance of medicine, the case of HIV seems to oscillate around the management of regimens and abilities to cope with a chronic condition mentally, medically and socially, as well as in professional life. If the

condition is well managed, teachers on ART are living much longer, and the negative impact of HIV on education is drastically reducing (UNAIDS, 2010; Vogl, 2012:11).

Undoubtedly, no education system can rise above the competency, motivation and conscientiousness of teachers (Bennell and Kwame, 2007). The teacher is a bridge between development and education. Since they are the largest civil service workforce in Zambia (Siameja, 2012), the health of teachers both casts more light on the role of African states in providing social welfare and helps us to understand workplace politics for government employees (Whyte, 2015). The high number of positive teachers stems from the fact that, as an educated group, teachers enjoy a certain level of social and economic status and privilege in Zambian communities; this makes them a risk group for contracting and spreading HIV (Kelly, 2000).

Development depends on health and education alike (UN, 2011), because the quality and effectiveness of an education system is centred on the health of its teachers. Teachers are key to meeting the educational goals of any given society (Siameja, 2011:2). National development therefore depends at least partly on education: the future supply of education will depend on the human and health dimension for effective public service delivery (UNAIDS, 2013; Risley et al., 2012:12). In the section that follows, a consideration is made of teachers' health in relation to HIV and the significance of their position in national development.

## **2.5 Theorising teachers' health, HIV and their role in national development**

Studies (Livingston et al., 2012; Wolfe et al., 2010; Whyte, 2015) exist that aim to explore HIV and government workers, but they do not specifically focus on the health of teachers (as civil servants) living with HIV. Effective interventions that aim at improving health are mainly incorporated into the education system (WHO, 2009). For example, investments in teacher training programmes may be ineffective and a loss of resources if teachers do not receive assistance and knowledge, not only on prevention issues but also about living with HIV.

The status of teaching as a vocation is an area of concern in many SSA countries (Butler, 2016). Two varying viewpoints on the teaching profession's status exist. First, it is perceived as a very attractive occupation due to job security, paid and relatively

plentiful holidays, diverse opportunities to make a difference in society and have more general social power, and opportunities for job satisfaction, and because it is a universal job which can be undertaken anywhere in the world. Second, teaching is seen as an unattractive career because the pay is not equal to the effort put into the job and there is a lack of consistent performance-based promotion. Although teachers are recognised as well trained and highly skilled, and are seen as being hugely influential in society, none of these factors result in them being prosperous, especially when they are also living with a chronic disease.

The two points above suggest that when mapped against other professionals such as lawyers, doctors and many more, views on teachers are differentiated from those in other occupations on the grounds of power and remuneration. In most cases, teachers are esteemed, acclaimed, trusted and respected on an individual basis. However, they are often not granted overall respect as a group, and hence are accorded low status. A teacher is not only an educator, but a custodian of personal growth and national development through the art of instructing, imparting knowledge and guiding learning for the attainment of set educational goals (Razak et al., 2015; Peretomode, 1992). Thus, the onus of transforming and delivering the curriculum to achieve educational objectives and national development is significantly shaped by teachers in Zambia.

Teachers and HIV itself play important parts in enabling and constraining countries' socio-economic progression. However, HIV prevalence rates in most African countries have decreased (UNAIDS, 2018). This reduction in prevalence rates is among the general populace and it is associated with high education attainment levels and prevention knowledge, as HIV education has spread across many countries (Mugendawala and Hagedorn, 2017; Moyo and Smit, 2017). This argument sounds logically valid, and is epidemiologically borne out in many countries, where HIV was established first among mobile middle-class urban dwellers with more disposable income and extensive socio-sexual ties, before becoming (as for instance in South Africa) a disease of the poor as HIV awareness spread among more educated and affluent groups (Endicott, 2019). But the Zambian experience shows that HIV/AIDS prevalence is at its peak mainly among the learned, including teachers (NAC, 2014). Also, although studies show an improvement in teacher infections and deaths due to HIV in Zambia and Africa, mental health issues are now a serious concern. Adams et al.

(2015) provide an in-depth analysis of mental health problems in London across the period of HIV treatment progression. Based on reports from clinical cases, the authors reveal increased anxiety and brain disorders which are associated with depressive chronic conditions while on ART.

Studies by Bonnington et al. (2017) and Wringe et al. (2017) looked at stigma as embedded in historical and biographical notions of time periods while living with HIV, and found that stigma manifests itself in various ways and at different levels. For these authors, disruption in care and non-adherence to ART are associated with stigma, as people living with HIV may feel uncomfortable with certain individuals, and a sense of being unaccepted might be triggered each time they take the pills. The authors maintain that eradicating stigma requires a consideration of the temporality of discrimination problems, designed for diverse stages of HIV care. These authors' findings are significant in showing the association of different stages of HIV and the transformations of stigma at each level of care. However, they do not relate these forms of stigma to their effect on mental health as associated by extension to care disruption and the termination of post-diagnosis care, an issue explored by this research. The mental health effects of HIV medicalisation have not been extensively assessed in Zambia. For instance, depression is not described or analysed as a long-term issue. Uebelacke et al. (2015) found that chronic pain while on ART was connected to depressive symptoms, but the authors conducted their study on individuals in the UK, a developed country, whereas this research focuses on a low-income country, Zambia, which might be different on issues that link ART and mental health problems.

In Zambia, there seems to be limited focus on mental issues as part of health. However, numerous studies (Doyal, 2016; Locock and Ziebland, 2015; Orza, 2015; White, 2015) have attempted to explain the link between long-term illness and mental health services. For example, Chuah et al. (2017) draw on an extensive systematic review of how mental health services can be integrated with HIV care. Although this study shows the importance of merging HIV and mental health services, it fails to use empirical data to justify the practicability of such interventions. Similarly, Dow et al. (2016) identify that mental health difficulties can affect ART adherence and increase HIV stigma. Dow and colleagues' study, although relevant as it was done in Tanzania, a neighbour of Zambia, focuses on young people. This is a sample at a different level of care, and the use of

structured questionnaires might have been limiting regarding how the findings were generated and analysed. This current research's focus is on adults, and it uses interviews that shed light on HIV and mental health representations that may differ from and build on the study reviewed above.

Other studies (Halkitis et al., 2017; UNAIDS, 2018; Rooks-Peck et al., 2018) have also reported that HIV mental health problems are related to comorbidity for those living on ART. Although useful for this research, the context of these studies was clinical and around care interventions in the West. This current study highlights some aspects of the Zambian context of mental health and HIV treatment management. Kim et al. (2017) found that non-adherence to ART among HIV positive adolescents in Malawi was associated with feeling depressed, forgetfulness, difficulties with travel, and stigma at home and outside. Although these findings are important, the reviewed study was about associated ART factors and adolescents, whose mental health may differ from that of adults such as those in this present research. Additionally, the use of questionnaires as a method in the reviewed study may not have given an accurate or in-depth representation of mental health as it relates directly to ART. Nonetheless, the finding is significant in Kim and colleagues' work that non-adherence has the potential to cause viral rebound and disease progression of drug-resistant strains of HIV that compromise treatment outcomes.

Additionally, Moyo and Smit (2017) found that head teachers and leaders lacked management skills and opportunities to train, develop and apply interventions that would minimise the psychosocial and profession impact of HIV on learning and teaching. The above study focused on head teachers, and did not comprise primary accounts of teachers who were living with HIV themselves. Hence, this study extends the discussion, as it draws on teachers' accounts of managing life on ART and their representations of being effective in spite of living with HIV. Cohen's (2009) study has shown that education systems thrive when classroom teachers are motivated and efficient. Similarly, Wanekezi et al. (2011) contend that the skills, creativity and industry of people in Africa, Zambia included, will be difficult if not impossible to build without healthy teachers and an HIV positive population of civil servants more generally.

Generally, a teacher is an agent of development, as he or she advances the frontiers of knowledge through academic, pedagogical and social roles. The academic role comprises teaching and supervisory duties. The pedagogical role includes instruction, evaluation and facilitation. Social roles include socialising activities which prepare students for the society's way of life (Carmody, 2004; Kelly, 2010). Studies (Darling-Hammond and Rothman, 2015; Ekpiken and Edet, 2014; Emeh and Ogaboh, 2010) have shown that this process of knowledge creation is mainly about the transformation of society and enhancing potential for poverty reduction, wealth creation and equitable distribution of resources, ensuring nutrition and health, housing and ancillary services, social security and welfare. Hence, teachers ought to be seen as a foundation of good and active citizenship, and the foremost architects of nation-building.

According to Wanekezi et al. (2011), education unlocks the door to modernisation and sustainable development, but the teacher holds the key to the door. Teachers help in the development of various skills and competencies that equip individuals in society to fulfil various roles, for example, in enhancing food production, improving transport systems, providing better and innovative health services, and widening the range of communication systems, all for the common good. Teaching is the important activity which makes possible the acquisition of knowledge and skills that are a mark of educated and enterprising individuals in any given society (Okemakinde et al., 2013). The skills, creativity, self-discipline and industry of people in a nation can be difficult if not impossible to develop without healthy teachers and good conditions of work, especially around emoluments (Buckler, 2016; Kalimaposo and Mulubale, 2015).

In this treatment age, for example, not all teachers in Botswana perceive HIV/AIDS as a serious problem within their schools. This is because of the concealment, insecurity and denial of identities and practices that relate to the disease, especially around procedures of ART (Bennell et al., 2001:20). The medical, social, economic, cultural and political factors seem to be bringing forth new micro and macro trends in teacher behaviour and effectiveness within schools and beyond, with significant national development implications in a country such as Zambia.

Having shown the significant role teachers play in development, none of the above literature shows how this role is enhanced, transformed or altered when a teacher is

living with HIV and on ART, an aspect that constitutes one of the core issues addressed by this research.

## **2.6 Chapter summary**

This chapter has reviewed the relationship between health, HIV and education, in Zambia and elsewhere. The literature reviewed here has shown that difficulties for teachers living with HIV are exacerbated by medical, informational and material resource factors. Several studies cited here have shown a strong relationship between health, development and education. Scholars (such as Kelly and Bain, 2003) in education show that teaching shapes national development. In this chapter, it has also been shown that HIV, which through its treatment in Zambia is now a chronic condition, is creating new possibilities and limits in education and national development trends. Health and development interact in complex and changing ways, especially through policies.

The challenges for the teaching profession appear from the literature not only to apply to improving their status and QoL by raising salaries; they also extend to reducing all sorts of barriers – even before considering health – that hinder teachers’ professional status and their capabilities for pursuing quality in the education system (Buckler, 2016). How teachers navigate through their academic, pedagogic and social roles can either disrupt or substantiate their views of the self and their collective identity, in both official contexts and informal settings. From the literature reviewed here, it seems that the functions involved in being a teacher are not correlated with a requirement to be healthy. Indeed, health is rarely addressed within considerations of teachers’ roles. In the literature in education studies, there seems to be a strong concentration on curriculum and methodological issues for effective education systems, and less work on teachers’ well-being. Yet the focus should indeed include teachers’ well-being, because a teacher who is unable to flourish personally is unlikely to be concerned about or able to pursue pupils’ own well-being (Tao, 2013; Butler, 2016:171).

This chapter has shown that teachers are national development agents and architects of the desired future for the common good of all citizens. This is through their role in imparting knowledge and establishing a skilled citizenry to meet national development goals and individual aspirations. But being HIV positive introduces major challenges.

These difficulties are not just encountered by HIV positive teachers in Zambia; they are general for all people living with HIV across the country. Without a cure – which is not currently in prospect, except in a very few cases of ‘functional cure’ – the management of HIV/AIDS will require long-term governing as a health problem. From a health perspective, there is an increasing belief that people who are HIV positive who receive treatment can live healthy and normal lives (Squire, 2007), even though their entire life pattern may include degrees of incapacitation, pain and social discrimination and distancing (Whyte, 2014) which create a new form of identity from that associated with their previous state of health.

In the next chapter, I explore the conceptual framework that underpins this study, through a literature review on the main concepts.

## **Chapter three**

### **Conceptual framework and literature review**

#### **3.0 Introduction**

The aim of this chapter is to discuss the relevant literature on the central concepts in this study. Based on the debates and scholarly works reviewed in chapter two around health, education and development in Africa, and especially in Zambia, this chapter attempts to resolve the issues raised across the reviewed texts. The dominant conceptual framework in this study emanates from the debates in chapter two, discussed here by considering citizenship in the context of HIV treatment through the concept of therapeutic citizenship. In this chapter, identity, chronicity and governmentality are defined, contextualised, critiqued and related to the concept of therapeutic citizenship. Reference is then made to the effects of HIV treatment among teachers in Zambia to bring this conceptual framework to bear on the empirical concerns of the thesis.

The chapter proceeds as follows: the first section introduces and defines the concepts that ground this study. The second part evaluates how and why the principal theories stated above can be hypothetically applied in society and everyday life. The third section concludes the chapter by framing therapeutic citizenship as a key concept around which all the four key theories of this study converge and can be articulated.

#### **3.1 Background**

Life on medicine renders the body central for understanding how the world is experienced while one is living on therapy. Theorising should thus start with, and be in relation to, various social facets of the body (Whyte et al., 2014:224; Shilling, 1993). Since the body is a biological unit, it must be given attention, objectified, cared for, trained, treated and optimised first by the person occupying it, then by medical practitioners and other professionals, and even by the state (Pallesen, 2014).

Illness and disease disrupt the functions of the body, but they do not extinguish the self; they merely alter identity (Pallesen, 2014:233). In this view, identity construction in HIV positive individuals, and those with other chronic conditions, emanates first and foremost from the bodily level, but is mediated by an individual's sense of belonging and level of participation and relations with others (Cooper, 2012). That is why these

interconnected concepts underly the descriptive models through which the data in this study will be approached in chapters six and seven.

Three central domains of the body and its immediate environment – governmentality, identity and chronicity – will be treated here as fundamental in discourses that shape any understanding of a therapeutic culture: a culture in which people seek, struggle with and negotiate the interpersonal demands of everyday life in the complex private sphere of a changing health landscape through narratives of identity construction (Elliot, 2014:85). This is because these concepts illustrate the dynamic processes through which bodies are converted to address an illness in a given space and time.

Thus, medicalisation and normalisation – although different and sometimes in conflict – are the overall theoretical context within which identity, chronicity and governmentality are considered within the therapeutic context of HIV citizenship. All of these foundational concepts, theoretically analysed here, can be linked to the perspective of body treatment as subjected by experiences and biosocial norms. I use these theories in reference to the consequences of ART for HIV positive citizens, which can be ‘muddled’ in the health successes and socio-economic challenges experienced by affected individuals and nations (Pallesen, 2014:233).

### **3.2 Outlining key concepts**

Many investigations in the social sciences have been inspired by Foucault’s conceptualisation of government. He used the term ‘governmentality’ to define a particular way of managing people in the modern history of Europe, in relation to the ideas and practices of the state. He later amended the theory to capture procedures used to govern people beyond political and administrative levels (Bulley, 2014). The concept of governmentality is relevant for this study because it helps explore the processes by which individuals or groups manage their medical conditions and represent their private, public and professional lives while living with HIV and on ART.

Identity is a concept that is often applied in a broad sense. It has been used with ambiguity to explore the collective present, past histories and life subjectivities in socio-political contexts (Goffman, 1963; Turner, 2000). Most of its usage concerns processes of cohesion that are driven by both political and social connotations of individual

uniqueness, group representativeness, belonging, power acquisition and recognition. Identity in relation to disease can be framed around prevention, care and long-term treatment as well as a sense of shared experience with others (Cruz, 2005). That is why when biomedicine transforms the awareness of a specific disease into a conscious health issue, it sets up grounds for socio-political manifestations of identity around that condition. The politics of identity in health and disease relates to bodily and mental capabilities. The effects of ill health are what determine whether people are considered normal or abnormal among what are supposed to be equals in society (Pallesen, 2014).

The chronicity of a disease, as the term suggests, concerns the health condition in relation to time, space and life events. Although chronicity as a concept can be traced to Western societies, which embrace individualised identities more than collective ones, it has been successfully applied in many non-Western cultural contexts to examine the impact of chronic diseases (e.g. Manderson and Smith-Morris, 2010). Curtin and Lubkin (1995) define chronicity in relation to illness as the irreversible presence, accumulation and latency of disease states or deficiencies. This involves the total human environment of supportive care and self-care, maintenance of function, and prevention of further incapacitation. The theory of chronicity generally deals with subjectively experienced long-term medical conditions in everyday life which may or not have a cure.

Therapeutic citizenship is framed here as a way of conceptualising subjects in relation to socio-historical particulars of the medicalisation and normalisation of HIV (Nguyen, 2008; Patterson, 2015). When synthesised in relation to the above concepts, therapeutic citizenship offers new ways of understanding medical solutions, normalcy and their limits in the everyday lives of teachers in Zambia who are on ART. According to Marshall (1950:10), citizenship entails an individual's full participation in public affairs and denotes an interaction among citizens; it also signifies a relationship between the individuals and the state. Therefore, the notion of citizenship is central here, and is taken in a direction that signifies taking part in public life beyond the conventional political sphere. Citizenship allows recognition of various identities in and among nations, as well as respect of individuals' human rights (Robins, 2008). It also distinguishes ways of living and making claims by individuals as well as groups, leading to an expansion of its conceptualisation so as to capture the diversity of forms of

practices (Johari, 2009; Steenbergen, 1994:2; Turner, 2000). As a concept, then, ‘citizenship’ is useful for exploring some challenges and successes of personal and group identity. With this in mind, ‘therapeutic citizenship’ is a phrase that highlights the biopoliticisation of populations and the self-management of bodies, especially in illness, which involves claim-making through local and international channels (Richey, 2006; Nguyen, 2010; Rhodes and Papparini, 2016; Whyte, 2012).

The individual and collective notions of the above concepts and their interconnected body politics offer possibilities for an interesting, complex and productive dialogue with *ubuntu* here (discussed in detail later). With this perspective in mind, identity is an issue that must be discussed at length – the task of the next section.

### **3.3 Identity: self and social aspects of medicine, health and illness**

The above issues, and those given earlier in chapter two, render identity, as contended by Allahar (2001), into a political and psychological construct that is socially located within relationships and individual codes of conduct. Historically devised sets of cultural and socio-political standards facilitate the creation and sustenance of all forms of identity. The complexity of identity in health is rooted in the ever-shifting and uncertain health consequences of HIV diagnosis. According to Woodward (2003), the formation of social and political groups within nations is mainly precipitated by shifting identities of the self. The concept of the self generally refers to an entity with psychosocial and physiological dynamism (Pallesen, 2014). The self derives from what people think, feel and know about themselves based on experiences and shared communal norms (Berzonsky, 2011). But this is contested, as there are different facets of identity beyond the self around which groups can mobilise for various reasons and at different times. In this regard, identity allows integrated ways of both thinking and acting in terms of the social and the personal, that is, lived experiences and related social facts which together create an internalised self-image (Woodward, 2003). Yet in terms of medicalisation, individuals define themselves and develop a sense of belonging through various diagnostic categories (Tucker, 2009) and the nature of their treatment, such as ART. These generic aspects can bring people together, as they are shared experiences of living with HIV. In this regard, HIV positive teachers who rely on medicine in order to function may define themselves in relation to their viral identities, and are less likely to be concerned with professional values or identities, such as

pursuing their pupils' well-being, due to their own health burden (Tao, 2013; Buckler, 2016:171, Flowers, 2010:114).

The link between biomedical identities and other forms of identities such as ethnicity is embedded in the state and HIV-citizens' relationships and interactions among themselves and within communities. The self and collective identity are made even more visible through demands for recognition based on chronicity – discussed in detail later – in daily struggles that require the intervention of policymakers and service providers alike. That is why the process of medicalising HIV is somehow directed by decision-making and support channels to integrate HIV diagnosis into everyday life.

Identity, when contextualised in relation to health, brings individual experiences and representations into consideration. Health and illness interact with more general social labels that become personalised, such as the image of an HIV positive person (Berzonsky, 2011:58). In many cases, lived experiences, especially of bodily illnesses, are used to construct routes and destinies for ordinary, everyday interactions within the broader social structures and intersubjective relations of identity over a life course. However, through diagnostic medical process one gets a renewed sense of self and collective identity. This is implicitly ratified by societal as well as medical discourses of normalisation predicated on self-regulation, efficacy, esteem and consistency.

The multiplicity of identity in biomedical processes leads to the categorisation of populations. For instance, being HIV positive can lead to a clustering of personal feelings of self-esteem and social co-constructions of identity that emanate from spaces such as schools for Zambian teachers on ART (Cast and Burke, 2003; Munachaka, 2006; Flowers, 2010). In politics, the dynamic consequence of shared societal values is capable of inducing another sense of nationality called 'ethnic citizenship', whereas in biopolitics it can generate what we refer to here as therapeutic citizenship (Nguyen, 2008), as discussed later. The notion of biopolitical identity and its linkage to various forms of citizenship is twofold: first, the transition from awareness of individual illness to health consciousness; second, the move from a specific disease to the formation of a group membership based on similar treatment regimens (Collyer, 2015). In this view, identity is both a process and an outcome of deeply felt personal illness and public

health records that give meaning to biopolitical and social life (Wahlberg and Nikolas, 2015; Whyte, 2015; Nakata, 2013).

The extent to which an HIV-citizenized person can develop either a positive or a negative attitude towards their own identity is shaped by resisting the normalisation of HIV amidst effective ART. That is why addressing people based on their biological condition in some communities is seen as stigmatising, discriminatory, shameful and undesirable in the search for social harmony and mental wellness.

Medical normalisation contravenes the many challenges that are faced by people with chronic conditions. Normalcy as drawn from medical discourses is a violation of the recognition of medicalisation, as it overlooks the psychosocial and sociocultural composition, for example, of living with HIV and on ART (Flowers, 2010:115). Two differing schools of thought have generally emerged in identity studies in relation to illness and health. The first is the view that identity labels inspired by disease and chronic conditions, just like ethnic identity in the African context (Mulubale, 2017), must not be embraced, due to the potential negative effects on individuals' self-esteem and the likely negative impact within communities (Whyte, 2012). The second position refutes the preceding contention and argues that describing populations based on health status and other biological characteristics, as opposed to nationality, ethnicity, race and many other factors, is a pillar upon which healthy nations can be built through knowing, prioritising and providing for the medical needs of some people in communities. The resources of a nation depend on the health of its citizens, and health-related identities are part of building those resources (Marmot, 2015; Wahlberg and Rose, 2015:77).

In a multi-ethnic society where tribal identities are prevalent, such as Zambia, representations of living with an illness compete with biomedical identities through language labels that are shaped by notions of sameness and difference when it comes to health status. For biomedically distinct individuals and groups to join mainstream society, they must first situate themselves as different (Flowers et al., 2006).

Differences in HIV medical identity for professionals such as teachers highlight the importance of social experiences that can facilitate the process of recognition and the incorporation of excluded groups based on their health conditions in workplace policy. Representations of health and illness cannot be given absolute meanings in diverse

social and political structures, because the effects of most medical transformations are psychological and therefore hidden (Cruz, 2005; Flowers, 2010:116).

Since HIV is seen as a deadly disease due to the lack of a cure, its medicalisation has not reduced the likelihood that those who are positive will be labelled a social biohazard. Since people with many chronic conditions must make conscious commitments to adhere to treatment for health or even survival, it is the institutionalisation of HIV through law which makes it (and its medication) different from other pandemics. This exceptionalism, and in some instances the history of the pandemic, has an effect on the presentation of the self in both professional spaces and social roles (Manderson and Smith-Morris, 2010; Flowers, 2010:117).

Nonetheless, identity derived from biomedicine appears problematic and compromising. Grouping HIV positive individuals based on their medical dependency may not promote social harmony, but can deepen the fragmentation of populations based on biopolitics within nations (Sabina, 2013; Nguyen, 2010; Parker, 2005). This has led scholars such as Ecks (2006) to claim that political (medical) pluralism – the presence of two or more peoples with the same (chronic health) condition – is a recipe for either social stigmatisation or the biomedically determined formation of groups. It is possible that people who suffer from certain illnesses are often given certain special opportunities and privileges, and this may lead to exclusion or inclusion, both socially and politically. Consolidation of identity founded on biological traits – for instance, sickle cell anaemia, sickle cell trait, or Tay-Sachs disease – and medicinal needs – such as those around HIV, diabetes or heart disease – can be useful for the (re)distribution of available resources into and across the health sector, and as grounds for claims for these and other resources (Rose and Novas, 2005).

While chronic conditions do re-establish forms of belonging through identity, it is more often the case that long-lasting illness weakens social networks and interrupts relationships over time (Pallesen, 2014:237). Foucault's work on sexuality and governmentality, for example, has inspired many identity movements. However, he was critical of the concept and promotion of fixed identities, calling rather for the dissolution of identity because of the subjugations and power relations in play over and between different others (Bulley, 2014). Contrary to Foucault's support of elastic

identities in response to medicalisation, for instance, identity in biopolitics is significant in the first place for recognition, integration and participation in public life. Being on ART is and can be used as a criterion for the struggle for acknowledgement, inclusion and respect by those living an HIV positive life, such as teachers in schools.

Although identity theory is significant for understanding human actions and spaces of relationships, it seems flawed for determining the extent to which subjectively felt and not enacted identities can manifest themselves in medical discourses. As a concept, it mainly looks at processes of constructing the self-image that are influenced by external entities, leaving out internal, ambivalent identities, such as the identities of those struggling to adapt to their HIV status. Individuals may at times deliberately process and evaluate self-relevant information before forming commitments and defining themselves, whereas sometimes they adopt and internalise the normative prescriptions of those around them and their subcultures (Berzonsky, 2011). The accommodation of a medically determined identity is itself drawn from individual physical and psychosocial histories of the impact of medicalisation over time. Indeed, in self-determination theory (Guardia, 2009), it is argued that the identity and obligations of living on medication are controlled by natural factors such as bodily incapacitation due to illness, an idea that is consistent when applied in the context of teachers who are on ART in Zambia. Their personal health and illness trajectories from diagnosis to treatment are key in forming their HIV status identities, coupled with socially determined norms of being positive. Living a medicalised life, such as being on ART, is tightly governed and thus confronts old identities, as it requires both expert knowledge and the formulation and implementation of intervention routines for a healthy life (Wahlberg and Rose, 2015). Moreover, many other identity constructions – related to gender, generation, age, religion and class, for example – intersect with HIV medical identities, biopolitically and perhaps outside of governmentality.

The idea of identity construction for HIV positive people has causal links to the governance of medical regimens and interactions. The interface between the social and the medical is crucial for understanding the agency upon which medical images of HIV are crafted in social spaces, such as the workplace of a school for teachers. In this view, the conduct of medical practitioners is directed by biomedical constitutions that normalise ART. Service users' actions in managing an illness's positive identity are

associated with these medical instructions, which can either fit into or be in tension with social structures. This therefore overshadows some psychosocial issues in the governmentality of health and illness in the treatment age, which is the focus of the next section.

### **3.4 Governmentality: a Foucauldian approach to understanding life on ART**

Foucault's perspective on government is embedded in his notion of governmentality. He defines governmentality as constituting a variety of techniques that encompass political government, forms of self-regulation (technologies of the self) and the 'conduct of conduct'. Emphasis on conduct implies the 'regulation of behaviours' (Bulley, 2014:1; Burchell et al., 1991). The phrase 'conduct of conduct' implies an understanding of how subjects are made and how power is exercised by individuals and groups through a given culture. In relation to HIV/AIDS in Zambia, the appointment of focal persons in districts, provinces and schools, in addition to other HIV projects endorsed and supported by the Ministry of Education, is itself creating a health education culture and is an indication of the governance model in the sector. The Ministry of Education in Zambia has also introduced HIV/AIDS topics in various curricula, and has promoted the creation of clubs for learners and a series of HIV workshops for teachers.

HIV as an occupational risk for teachers led the Ministry of Education in Zambia to develop its own AIDS work policies in schools (Bennell, 2003). The institutionalisation of an illness such as HIV is similar to having a constitution that governs the actions and behaviours of a given population. More and more positive teachers are now engaged in the HIV school community by sharing their experiences, even becoming activists through technologies of the self (Foucault, 2008), in other words, by living with HIV and on ART while performing their roles. Thus, through confession (disclosure) technologies they become respected participants in the broad HIV community inside and outside their schools. Zambian school administrators appear to be consciously, albeit slowly, making their school communities safe havens, with reduced risk behaviours and reduced stigma for teachers as well as learners who are receiving HIV medication (Kelly, 2000; World Bank, 2009; Moyo and Smit, 2017).

Contemporarily, and with the upsurge of chronic conditions worldwide, as healthcare has become more accessible and lifespans have increased (De-Graft et al., 2010), health

has increasingly become more of an individual responsibility than a public issue. This is especially the case with privatisation on the back of structural adjustments. This move brings us to what Foucault called technologies of the self – in this case, extensions of medicalisation that place the biomedical governance of the body increasingly in the realm of self-care. Foucault considers medication as a culture which has its own body of knowledge, and as a way of knowing that has evolved in conjunction with technology and in isolation from the sociopolitical norms of affected individuals and groups (Tiefer, 1996; Foucault, 2008; Squire, 2013). Foucault's work broadens our understanding of subjectification, a concept that takes individuals as co-authors (with external influences) of their own identities, even in the course of medicalisation. Foucault extended his ideas about medicalisation by arguing that the process of subjection is a negative force through which individuals are made subjects against their will – such as when taking medicine on a daily basis. This constitutes the various versions of the social and natural worlds which are fundamental to the medical surveillance of bodies (Ellis et al., 2013) and identity construction (Goffman, 1963; Foucault, 2008).

The consequences of disease for the collective and individual are diverse. Governmentality here is about exploring the diverse ways in which people (teachers included) on curative treatments (and others) feel and are controlled – disciplined – not only within and around a medicalising clinical encounter, but also in the perceived expectations of their own social milieu (such as a school). Foucault's concept of governmentality has advantages in theoretical terms for understanding how HIV positive teachers in Zambia manage themselves and are governed by school rules. The concept typically reveals indirect as well as direct medical and other techniques used by the state, civil society and medical practitioners for leading and controlling individuals without being responsible for any unexpected outcomes of technologies of HIV medicalisation. It is through these wide-ranging and often invisibilised techniques that the treatment of HIV takes place. There is an increasing tendency to portray social and psychological phenomena as normal medical problems (Nye, 2003). This is due to the fact that medical governance is one form of the naturalisation of HIV that is now shifting responsibility in nations for citizens' health from the state into the domain of individual self-management and sufficiency (Squire, 2010, 2013). At the same time, governments operate powerfully by medicalising governance at the national policy level. The HIV work policy for teachers in Zambian schools, developed in 2005, is an

example of state intervention on health matters affecting individuals, but has potential for disrupting activities on a larger scale (Ministry of Education, 2012).

Foucault's theory of governmentality has been challenged, and is criticised for attempting to hold a discussion all at once on too much and ending up with too little (Lemke, 2001). The theory seems flawed in its attempt to identify core characteristics of modern medicine through a reductionist approach similar to the very health issues it seeks to interrogate (Bulley, 2014). Additionally, his approach can be criticised for being too Euro- and ethnocentric. However, patterns of conduct and self-regulation techniques in Foucault's theorisation of technologies of the self in relation to medicalisation can be universally applied and grasped clearly by thinking of governmentality and chronicity in a relational sense.

In spite of the noted weaknesses, Foucault's theory of governmentality uncovers the subtle obligatory duty to rules that are for the public good rather than individual well-being. For example, teachers who are on ART are required to teach even if their medical review appointments clash with their class timetables. Hence, temporality issues are intertwined with the power aspects of governing long-term health conditions. In the section below, the concept of chronicity is discussed.

### **3.5 Chronicity: time, social and management factors in HIV**

The prominence of chronic health conditions in nations is a global concern because they pose serious health, economic, social and political challenges for individuals, households, communities and nations (Olmen, 2011). In the global South, especially Zambia, the chronic nature of the HIV pandemic will continue to change the macro and micro socio-economic structures as those affected by and infected with HIV cope with the condition (Calvin, 2011). Differences in generations of HIV effects is a chronicity issue that studies such as Street et al. (2016) in the global South relate to transmission and risk prevalence based on age differences. Also, Franklin et al. (2019) focus on generational differences in access to health among transwomen. The study concludes that with age, medical resources become not only important but complex and changing. Although not directly about HIV medical resources, this study shows that healthcare involves time factors, relations and management that enhance well-being among different genders, age groups and sexualities in the global North. Chronic illnesses such

as HIV have been so imbued in global structures and international geopolitics that they have gone through significant changes that are reducing bodily incapacitation and deaths around the world (Cooper et al., 2013; Yach et al., 2004; WHO, 2015:20).

Furthermore, Manderson and Smith-Morris (2010) argue that several areas of life are affected by the chronicity of medicalisation. These areas include systemic poverty, interpersonal relationships, management of biological and epidemiological phenomena, and subjective time experiences. However, the above aspects are interwoven with three key elements of chronicity: disease or health management techniques (large and small scale), social phenomena, and time. These elements are discussed one by one in the sections below. While HIV can be broadly categorised as a chronic disease, its complex prevention and treatment needs make it unique in comparison with other chronic health conditions (Colvin, 2011:4).

The first of the above factors is the management of disease for a healthy life. The idea of chronicity expands the understanding of ‘disease’ time versus ‘illness’ time, and of how these blurred categories of time are managed and have different effects, largely due to medicalisation. Illness is more of an ‘experience’ than disease, which can be determined by biomedical methods ranging from clinical observation to physiological testing and culturing. Illness depends on the phenomenological examination of personally experienced distress (Curtin and Lubkin, 1995).

To manage a condition in terms of chronicity is to stabilise a person’s condition such that they can be diseased yet not ill – as with certain types of cancer, or indeed with HIV, where the temporality of being HIV positive and becoming more and more immunologically compromised does not relate consistently to the temporality of experienced HIV illnesses.

The focus of managing chronic epidemics appears to be more biomedical than medico-social through techniques such as rehabilitation, prevention, palliation, risk constraint and even rights to be supported. The biomedical aspect involves medicine as it relates to the body that has an illness, whereas the medico-social is about managing the disease using the integration of both medicine and social aspects. Therefore, the practices for sustaining a healthy life whilst living on medication for a chronic condition, as shown in

De-Graft et al. (2010), have two special effects: many chronic conditions whose management changes the meanings of the ‘biological’ appear less socially contextualised; and the strong sociocultural embedding of HIV foregrounds how its management over time changes ‘biological’ categories. The management of HIV is highly and increasingly biomedical – and successful – and that seems to reduce its biological determinism, as with other chronic conditions.

However, in addition, HIV is highly contextualised by sociocultural dynamics, given the way it is transmitted and because of its epidemiological patterns, which require the reorganisation and integration of health services, self-management and behavioural changes. For instance, within contemporary debates on HIV, it is often argued that the emergence of a pill called pre-exposure prophylaxis (PrEP); which protects from HIV infection, availability of and access to ART, medicalised prevention and transmission programmes, and the creation of activist lobby groups around treatment are changing the meanings and life patterns of being HIV positive or negative (Whyte et al., 2014). With medicalisation, the number of survivors who need complex treatment and medical care increases with long-term successes in treatment.

The HIV-biomedicine relationship is unique compared with that around conventional treatments of chronic illness such as diabetes or heart disease, because it requires the acquisition of a certain level of medical knowledge and social skill for a healthy life (Yasin, 2012). Most Zambian teachers work in social spaces; thus they are the subjects of policies, interventions and information that alter social behaviours in the management of schools (Kelly, 2000; Mulubale, 2018). This implies that the success of ART for HIV positive Zambian teachers is determined by resources and local contexts of policymaking around health which can influence how individuals are able to effectively self-manage their chronic disease.

The second area of chronicity involves social factors. Studies have shown that the social support base for people living with a chronic health condition determines the level of treatment effectiveness (Squire, 2010). Social support, or the lack of it, for a range of chronic illnesses – such as cancer and depression – is linked to high mortality and chronic illness treatment withdrawals (Yasin et al., 2012:4). Marmot (2015) argue that the health of people improves when they receive functional support, such as from

family. Although self-management is key, society has a bearing on the process of patients' self-determination and commitment to well-being (Curtin and Lubkin, 1995; Peterson and Somit, 2017). In Zambia, it seems teachers' access to biomedical and social technologies relies partly on their social status. Government employees – teachers included – who live 'normal' lives whilst on ART are those whose chronicity has been accepted by their social networks, and who are receiving both functional and structural social support through companionship, peer groups and informational links (Whyte et al., 2014). Help in the medicalisation process ranges from encouraging people to test, to motivating them to get onto a treatment programme. In Uganda, for instance, the sociality that keeps infected populations resilient, even in sickness and long-lasting treatment, is the support of kinship, friendship and partnership ties (Rabinow, 1996; Whyte, 2012). Similarly, teachers living with HIV in Zambia seek to be socially accepted, and sometimes conceal their HIV status due to stigma and the absence of standard social security and occupationally related incentives for medicalisation through ART (Kelly, 1999).

The third area of chronicity relates to time. Adjusting to bodily limits, disruptions and medication routines under HIV treatment is something that is learned over time. Time plays a significant role in shaping biomedical practices, and it defines patients' everyday life experiences away from clinical encounters (Whyte, 2012). Chronic illnesses, such as HIV among teachers in Zambia, require the ability to adapt to changes in terms of the length of an illness, and the passion to thrive whilst individually managing and negotiating different identities generated by the disease and its subsequent treatment (Kelly, 2000). Within the chronicity perspective lies the idea that any disabling condition, such as alcoholism and related long-term health or even addiction illnesses, can lead to modified lifestyles (Manderson and Smith-Morris, 2010).

From the discussion above, each domain of chronicity appears interrelated. This is because ripples of chronicity range across social isolation or integration, physiological or psychological limitations, independence or dependence, enforced or forged self-images and modifications of identities, to economic pressures and the episodic fear of death among sufferers (Levy, 1979 in Curtin and Lubkin, 1995). The changes in one's life due to medication are shaped by coming to terms with one's past, present and future

health conditions. How one makes the links between a changing life and one's chronic condition is facilitated by seeing life temporally, in terms of adaptation and self-conduct. There is no certainty of continued health stability in living with a chronic condition. Also, a person's social clock is disrupted by unexpected experiences of an illness (Morris et al., 2012), which can overturn one's life prospects at any stage. Mostly, then, chronic conditions have less to do with the past and the projected future than the present. Mead's (1932 in Collyer, 2015) theory of temporality argues that time and history have no impact on long-term chronic health issues. He argues that chronic conditions are timeless, due to the focus on the present of the infected and affected person. Living with a chronic disease is emphasised by experiencing and embracing the present identity that is either imagined or forfeited. Self-construction in chronicity is based on the existing reality that is in the now – the present; this implies that time – past and future – are at some points irrelevant in health and illness.

Although the conceptualisation of chronicity above appears relevant for deducing the trajectories that are reshaping and normalising HIV, the concept is not devoid of critique in current scholarship. The prevailing narratives of chronicity point to a view of chronic diseases as manageable, lifelong and invisible, through acute illness and reduced bodily capacity. The traditional view of chronicity outlined above does not help to fully describe life on ART for HIV positive individuals. The uncertainty tied to life on ART, and the social expectation of the invisibility of chronic conditions, can be a basis for stigma in HIV medicalisation. Temporality effects in biomedicine are homogeneous and linear; thus medical narratives of chronicity appear problematic and inaccurate, as social dimensions are often unaccounted for. The understanding of a chronic illness such as HIV requires not only an individual account of experiences, but must also consider the effects of collective actions and interpretations of living a medicalised life with an incurable disease.

The concept of chronicity can be flawed if used in low-level analyses and short-term perspectives on HIV medicalisation. Therefore, the theory ought to be contextualised in relation to long-term biomedical conditions that show no visible signs of being acute. New ways of understanding chronicity must be inspired by the medicalisation of invisible, non-physical disorders and lifelong conditions, such as the contemporary phase of HIV marked by a permanent reliance on ART.

Forms of ART representations in this era provide an opportunity to rethink notions of identity in HIV subjectivities based on a specific cultural context. Although not one of the key concepts, *ubuntu* becomes an appropriate supplement to identity and a collectivised cultural form of HIV chronicity in communal forms of governmentality.

The repurposing of therapeutic citizenship here requires the simultaneous inclusion of the concepts of *ubuntu* and decoloniality in Zambia. *Ubuntu* is brought into the picture because it draws on personhood, humanness and morality. It is a humanistic orientation towards fellow beings in that it envelops key values of group solidarity, compassion, respect and human dignity (Ratele, 2016). Decoloniality is useful for framing therapeutic citizenship in our time, due to rising concerns to (de)globalise the production of knowledge and social discourse outside Western domains by utilising other disciplines (Masing, 2018), especially in the context of medicalisation and normalisation.

### **3.6 *Ubuntu* and chronic diseases: ‘I am because we are, we are because I am’**

When it comes to questions of illness and health, the notion of *ubuntu* remains under discussed in the literature. *Ubuntu* was first chronicled by H.H. Hare in 1846 (Broodryk, 2002). The word ‘*ubuntu*’ was popularised by Jordan Kush in the 1950s. It became, through different expressions, a political ideology in Malawi (*uMunthu* refers to taking responsibility for others), Zambia (*tiyendepamodzi*, which refers to moving as one people), Zimbabwe (*nguni bantu*, translated as ‘human kindness’) and South Africa (*ubuntu*, translated as ‘humanness’) from the 1960s to the early 1990s. Most notably, in South Africa it was a unifying idea enshrined in the country’s Constitution of 1993. For Zambia, the ideology of *ubuntu* was deeply rooted in the political slogan ‘one Zambia, one nation’ that was used in the humanist movement immediately after independence in 1964 and under the leadership of Kenneth Kaunda, Zambia’s first president (Kaunda and Morris, 1966; Torgovnick, 2013).

Therefore, at the core of *ubuntu* are human relationships and interactions. *Ubuntu* is akin to how one operates in a society or a world guided by a humane heart that recognises and deeply reflects on ‘I am because of you’ (Tutu, 1999:34). Hence, *ubuntu* is rooted in various African cultures, particularly the Bantu-speaking peoples. But the

primary concern in the application of this life philosophy is nurturing relationships with other people, regardless of socio-economic status (Letseka, 2012) or biological and medical conditions. Hence, with advances in HIV treatment, how people in African communities relate outside Western notions of identity is under-researched and perhaps not known.

As a fundamental characteristic of the African world view, most scholars have grappled with the interpretation of *ubuntu* in Western contexts or languages, as the notion of *ubuntu* is difficult if not impossible to accurately render in a (Western) foreign language. As a classical African philosophical concept, the word '*ubuntu*' should not be given vague intentional interpretations which demean its relevance. It is an ethical or humanist ideology, referring to the necessity of unity and the removal of self-serving practices in order for the human race to evolve, exist peacefully and especially to prosper.

Democratic rhetoric and liberal practices in education in African nations since the early 1990s have generated debate on the preservation of cultural values. This literature portrays *ubuntu* as an epistemological paradigm that influences moral behaviour (Nkondo, 2007; Metz and Gaie, 2010). However, two conflicting scholarly traditions have emerged on this subject. One is the view that *ubuntu* is a comprehensive, and ancient African world view premised on the principles, values and respect for humanness. Those who are for *ubuntu* (Broodryk, 2002; Letseka, 2012; Metz, 2007) point to its rich moral propositions, and regard it as a public policy matter. For example, *ubuntu* is regarded as right action theory; other writers such as Teffo (1994) hypothesise *ubuntu* as having consistent moral value in the face of hardship. The other group of scholars refutes the preceding assertions by arguing that *ubuntu* is not a feasible socio-ethical model of life in democratic societies. This is because it embodies an imaginary tradition that aims at reducing or eradicating chronological notions of time (Enslin and Horsthemke, 2004).

The ideas advanced for *ubuntu*, as opposed to those against it, seem consistent. *Ubuntu* draws on personhood, humanness and morality. It is a humanistic orientation towards fellow beings, in that it envelops the key values of group solidarity, compassion, respect and human dignity. The spirit of *ubuntu* revolves around respect for human dignity, and

thus opposes hostility and embraces compromise. As an ancient African, humanistic and normative concept, *ubuntu* encapsulates values (kindness, generosity, compassion, respect, altruism, courtesy, benevolence, caring and having a heart for others), and is based on moral norms (Broodryk, 2002:13; Letseka, 2000:180, 188). This is why societies are seen to embrace humanism (*ubuntu*) as defined by a personal consciousness of *botho*, which entails treating each other with a sense of fairness and justice. In this regard, Africa, like the rest of the world, is not homogenous, due to its geographical, political, socio-economic and cultural slants. However, the essential cultural fact of life and living in Africa lies in the diversity (with *ubuntu* at the centre) and not sameness of cultures (Appiah, 1997:47).

The centrality of humanism in most African societies embodies oral historical recitations of family and communal life passed from generation to generation, whose knowledge is highly valued and treated as a signifier of collective and individual identity. In this vein, Letseka (2000, 2012) contends that at the heart of the debates on *ubuntu* is how African peoples perceive it as a world view that embodies their notions of morality and personhood. Although Letseka's works are vital in showing the concept from a personal and wider-world point of view, the literature does not explore *ubuntu* as an expression of shared pain, wealth, salvation and more, especially in terms of health and illness. This current study examined individuals as rooted in a community that defines personal identity in relation to the well-being of the community, even in chronic health conditions.

The fight against HIV/AIDS in the early years of the pandemic had the *ubuntu* concept as one of the intervention strategies, especially for ending stigma in African countries such as Uganda and Zambia (Tarkang et al., 2018). The ideals around respect and dignity for human beings formed a basis of various programmes. *Ubuntu* tenets described above have been applied in both prevention and control programmes for HIV/AIDS in SSA. However, these ideals of *ubuntu* are not widely promoted in HIV treatment programmes, except in prevention and control activities. For example, Uganda in the early 1990s adopted a multisectoral approach following the high mortality rates associated with HIV-related illnesses. Through collaborative efforts involving collective action by political and religious leaders as well as community-based support partnerships, heightened *ubuntu*-spirited efforts built for example on the

campaign motto of the Love Life, Stop AIDS programme, which won Uganda international accolades for the impressively inclusive response it received by comparison with other African countries' actions in the fight against the pandemic (Ugandan Ministry of Health, 2015). That is why the human ethics and moral scope implied by *ubuntu* in this research are examined in relation to biomedical conditions and citizenship.

Paterson (2010) argues that the Church plays a crucial role in promoting this sense of humanness in Zambia. For example, both religious and community leaders have advanced messages against stigma to reduce discrimination for people living with HIV. The approach to communal efforts helped normalise HIV and sustained the fight against AIDS within and by religious and other community groups in South Africa (Tarkang et al., 2018; Nguyen, 2010). However, these programmes were set for a different time period with limited access to effective treatment. Some of the efforts of the time cannot be applied in the current era of treatment and invisible HIV. Hence, this study attempts to relate *ubuntu* to the context of HIV medicalisation, and not the prevention or control issues focused on in the literature.

Nonetheless, the concept appears problematic, as it talks less about the dualism of long-term illness and culture. This concept seems limited when it comes to looking into individual representations of external and internal feelings for those living with long-term health conditions and on medication, such as HIV and ART respectively. The function of *ubuntu* in this study and in relation to the above overview is to inform debate and extend the practice of communal values in HIV as a chronic illness, as well as health in an African setting. The concept is useful here for social identity as experienced by individuals within wider society. In relation *Ubuntu* in this study's findings may support or challenge how biomedical discourses conceptualise and set an understanding of managing health and illness using lenses of Western and African interventions.

Having looked at identity and an alternative Afrocentric form of governmentality, in the following section an attempt is made to conceptualise HIV citizenship in its new therapeutic context in a way that also recognises the concepts discussed above. As has been noted, governmentality makes possible the discernment of patterns of conduct and

self-regulation by teachers, and even other citizens, who are living with and affected by HIV in Zambia.

### **3.7 Therapeutic citizenship: its conceptualisation and interconnections**

In his work, Vinh-Kim Nguyen focuses on people living with HIV and introduces the concept of ‘therapeutic citizenship’ in order to outline humanitarian efforts to fight the scourge (Nguyen 2008; 2010). Through his 1990s research in West Africa, Nguyen revealed the extent to which AIDS was transformed into a global industry enmeshed within the development sector, leading to humanitarian projects on effective treatments that appear to have birthed new forms of subjectivities, such as AIDS activism, drug-resistant viruses and therapeutic communities. Most HIV positive individuals in Nguyen’s (2010) sample had a treatment predicament, and appealed more to donors than to the state. This was on a global platform through what he called ‘confessional technologies’, which were simply personal stories of disclosure about living with AIDS. Nguyen’s conceptualisation and relation of therapeutic citizenship was meant for a particular era and geographical area, and thus it appears quite context-specific, as it focuses on access to medicine and difficulty of treatment access alone (Nguyen, 2008). However, disclosure as a technique in current practices of HIV treatment continues to create a membership base at both global and national levels (Rhodes and Papparini, 2016:505). The concept of therapeutic citizenship involves the broader social, political, economic and cultural implications of stratifying citizens on the basis of discourses and practices of biomedicine and biopower.

However, a collective way of addressing HIV issues can be made possible through technologies of confession. This can be associated with HIV disclosure, which has been investigated by a large body of literature (Camlin et al., 2017). Bonnington et al. (2017) find that stigma is changing the forms of disclosure that people embrace in the treatment era. This view is supported by Bernays et al. (2015), Vincent et al. (2017) and Wong et al. (2017), who explain that being open with their HIV positive status leads to support, especially with medical elements, for young people.

There is a relationship between support, adherence and disclosure. Studies have shown that family’s and friends’ help is useful not only for managing but also for self-acceptance (McDonald et al., 2015; Skinta et al., 2015). However, according to Tarkang

et al. (2018), communal forms of support improve the self-esteem of people living with HIV and create a sense of belonging. The literature suggests that family and communal forms of support for those living with HIV have good adherence outcomes (Qiao et al., 2012; Squire, 2010, 2013).

Early studies such as Barnett and Blaikie (1992) and Squire (2007) suggest that in the early years of the pandemic's devastating effects, support from various stakeholders was abundant. However, any form of help, as in Lock and Nguyen's (2016) argument, requires some form of testimony to an HIV positive identity. Studies tend to isolate the two and focus greatly on adherence (Lyimo, 2013; Mweemba, 2010; Nixon et al., 2017) and support in HIV. Additionally, studies (Bond et al., 2016; Murthy, 2016; Pingel and Bauermeister, 2018) have shown that the role of the Church appears to be diminishing in the fight against HIV, and that HIV positive people feel uncomfortable seeking or talking about HIV in their congregation due to condemnation and the fear of stigma. However, there seems to be a gap in the literature in terms of showing clearly how improved health is changing citizens' needs. This is reducing sources of help and layering important forms of support – issues that this current study explores in relation to therapeutic citizenship.

Recent evidence suggests that disclosure of HIV status is a burden and career constraint (Sanden et al., 2016; Henning and Khanna, 2016). The culture of shame and embarrassment at work or in the community has been analysed by Ho et al. (2017) and Bond (2007). In their paper, Hutchinson and Dhairyawan (2018:68) contend that shame over HIV can make individuals not disclose their status, to avoid facts about previous sexual behaviours that may have led to infection. Although useful, the authors do not use empirical work to support their ideas alongside philosophical work. This research will therefore explore whether shame leads to isolation and withdrawal from social environments when one is diagnosed with HIV within a context of therapeutic citizenship. Additionally, Elwell (2016) found that the relationship between HIV privacy and disclosure made participants talk about hiding medicine and registering for ART with a hospital that was far away from their place of residence.

In the same vein, Kim et al. (2017) note that disclosure to the wider community is a resource for mitigating adherence problems, as one can be reminded by others to take

one's medication, particularly because of 'forgetfulness'. This is seen in Presson (2016), ART affects cognitive abilities to remember, a mental health problem that is untreated for people living with HIV. Additionally, other works have shown that disclosure is a source of power to control social narratives about being HIV positive. Studies by Bell et al. (2016), Bond (2010) and Lyimo et al. (2013:102) have all suggested that disclosure is a process, and that people living with HIV trust and seek acceptance by confessing their status first to family and friends, as also suggested by Squire (2010). Opening up to family and friends who would encourage and offer support is a key finding that Horter et al. (2017) identify as a central motivating factor for those living with HIV.

Individual biopolitical and biomedical claims are recognised and respected based on a shared biological condition. Under the extended conception of therapeutic citizenship applied here to HIV/AIDS, biological characteristics, as they are socially mapped and acted on, matter. The relationship between therapeutic and biological citizenship is twofold: individualising and collectivising. Both are individualistic, because they focus on the body and personal strategies for managing illness. They are collectivising, because they act as conduits for establishing communities, group engagement, and civic participation and activism. For example, therapeutic citizenship among HIV positive teachers in Zambia involves issues such as support for treatment, which sustains individual and collective identities through symbols of hope and manifests itself in social spheres and biomedical arenas (Rose and Novas, 2005:5). Social relations in care activities based on diagnosis and treatment are bringing people living with HIV closer to the state and communities (Kyakuwa, 2009 in Whyte, 2012). Teachers in Zambia appear to recognise and connect with the government through its programmes of free access to testing and treatment.

Living with HIV and/or thinking about those who are ill involves addressing the physical and mental effects of HIV treatment on individuals and the whole society. In contrast, therapeutic citizenship is clearly about both solidarity and the contestation of power-brokering relations, as seen in relationships from the interpersonal to nation-state relationships, and it has to include attention to the socio-economic inequalities prevailing among citizens in most countries as well as between countries and regions (Ratele, 2016).

How does the picture of HIV fit into therapeutic citizenship narratives? First of all, HIV is increasingly seen as a chronic condition, due to the availability of and access to effective, early, long-term treatment and the management of side-effect (De-Graft et al., 2010). Second, through support groups to access treatment and other benefits, HIV medicalisation becomes a political and citizenship issue. Third, as a permanent health condition, HIV is characterised by the stigma encountered by sufferers, and is strongly linked to their cultural and social life – for instance, factors of race, religion, gender and even socio-economic class. In economic terms, the HIV pandemic is not limited to ART drug supplies, but also requires colossal resources to be managed in prevention, treatment and care for infected and non-infected citizens. In the context of African countries, Zambia included, government employees such as teachers are embedded in global and national political sentiment, evidenced through policy and in popular media, as well as in social relations at all levels, from the interpersonal to civil society (Whyte, 2012).

Therapeutic citizenship comes with benefits and limitations to citizens' public and private lives. There is an increasing medical, cultural and social understanding of living with HIV. Yet, isolation and other bodily limitations, even fatality, are associated with being HIV-citizenized. This is because most discourses and practices for people living with the virus are intertwined not only with an HIV positive identity, which frequently continues to involve stigmatisation, but also with other forms of acquired self-image, sometimes associated with a professional identity – for instance, being a teacher. At the same time, claims made and privileges enjoyed based on being an HIV positive teacher (or indeed sick because of other illnesses) seem in some circumstances to be outweighing entitlements on the basis of poverty, systemic inequality, gender, race, ethnicity and other forms of injustice that are identity-driven (Nguyen, 2008:143; Patterson, 2015). These factors can potentially create other forms of economic interest and categories of 'citizens among citizens' – biopoliticised populations – in the same nation-state and even on the global level (Squire, 2013:90–104). That is why most HIV activities are mostly externally funded in many countries such as Zambia, thereby allowing donors to shape the international context of therapeutic citizenship. Similarly, donor provision is creating global groupings of populations through clinics and the universal 'projectification' of HIV/AIDS (Patterson, 2015:2). Manufacture,

procurement, distribution and access to ART is connecting HIV as a biomedical issue with the political and economic processes of nations.

With the above in mind, therapeutic citizenship can be linked to political citizenship. Medically reliant individuals reform and understand aspects of citizenship such as national identities, responsibilities, rights, obligations and entitlements to become active citizens, and this exacerbates the need to extend notions of therapeutic citizenship to capture political aspects of citizenship such as rights (Steenbergen, 1994:2). Individuals living with HIV, at least in Zambia, do not often act and mobilise on their right to health – embedded within political citizenship – and hence are not likely to make health-related demands on the state. Teachers as therapeutic citizens in Zambia appear not to recognise the social contract they have politically with the state, as the role of the state is invisible, since demands are placed on non-state actors such as donors or pharmaceuticals (Whyte, 2012; Patterson, 2015). HIV advocacy has somehow taken a much broader approach, resulting in notions such as the para-state, which implies an absence of full ideological state apparatus in health matters, especially in non-developed nations such as Zambia (Mbali, 2013). Today, in most liberal political contexts, health politicking has nurtured citizenship stratification between those who are living with and without HIV (Squire, 2016). The biopolitics of HIV has allowed people to offer solidarity and identify with each other based on shared experiences (Patterson, 2015:3) just like other citizenship aspects held in commonality within and between countries.

HIV's medicalisation is time-based, since it demands a therapeutic 'fix' which requires colossal resources, especially monetary, for continual maintenance. This is evidenced in Zambia's huge sums of resources allocated to the procurement of ARVs (Ecks, 2005:244). However, it cannot be assumed that medical control methods for chronic conditions can create habitual practices in societies full of differentials.

Therapeutic citizenship highlights notions of inclusion and exclusion of the infected and affected. Through a citizenship that is medically determined, one can gain access to resources, and enjoy rights that other national citizens with other forms of chronic illness – such as diabetes, high blood pressure and more – may not be entitled to. In this case, HIV positive people, such as some teachers in Zambia, have access to free drugs; in some instances, they have received food stamps and sponsorship to attain an

education, as well as empowerment funds (Mweemba et al., 2010; Siameja, 2011). Additionally, this form of citizenship helps to find solutions by providing easily identifiable human subjects, since infected people are put under medical surveillance. Most scholarly works, such as Nguyen (2008, 2010) and Whyte (2012), tend to focus on narrow conceptualisations of therapeutic citizenship by looking more at the biomedical implications of medicalisation than at the social dimensions within political and cultural spaces of identity and belonging. They also address highly specific country and time contexts. The contemporary situation of 90-90-90 goals – or more modestly, in the Zambian case, widespread ART access and efficacy – means, too, that the notion of therapeutic citizenship needs to be readdressed.

The biopolitical context of therapeutic citizenship, used in this thesis, arises from the tacit integration of chronicity, which seems to fit with individual identity based on the governmentalisation of a self-image acquired through illness and often consequent medicalisation. The complexity indicates the potential disruptive and perhaps reconstructive effects of ART on citizens' everyday lives through the notion of therapeutic citizenship (Murray, 2007). Therapeutic citizenship as a concept thus allows us to think through identity, chronicity and governmentality, about large structures of political, economic and sociocultural practice around HIV, as well as about how individuals with chronic conditions forge new forms of resilience, resistance, acceptance and belief about their illness and treatment effectiveness (Squire, 2007).

Therapeutic citizenship here is conceived as relationally shaping understandings of the politics of chronic conditions in this treatment era. HIV has transformed societies, as it is a global issue with the long-term health implications tied to taking medicine, every day and on time, for life (Rhodes and Papparini, 2016). In this, and based on their conceptual context, HIV positive teachers experience 'on and off' episodes of wellness and illness, both physically and mentally, but how this affects their roles in schools needs empirical investigation.

Therefore, this research, therapeutic citizenship involves the broader social, political, economic and cultural implications of stratifying citizens on the basis of discourses and practices of biomedicine and biopower, beyond the field of HIV (Rhodes and Papparini, 2016).

### 3.8 Chapter summary

The preceding sections in this chapter have explored how the governmentality of this disease, turned chronic, involves an identity that is biosocial and biopolitical, and an outward manifestation through conduct of an inward emotionality. It has been argued here that being HIV positive and on ART can change the images and relationship networks of individuals and groups.

Through some new theoretical insights highlighted in this chapter, it can be ascertained that use of ART is directly and indirectly changing knowledge (or understanding) of the HIV pandemic. This change in Zambia means that HIV is now a chronic illness that seem to be creating a form of therapeutic citizenship.

This chapter and the one preceding it make significant theoretical contributions that extend our understandings of therapeutic citizenship. The central concepts discussed here, including *ubuntu*, make a central focus for chronic conditions research in light of citizenship because of the exponential increase in biomedical technology, which points to what appears to be a transformed ‘state-citizen’ and ‘citizen-citizen’ relationship based on biomedical, biopolitical and sometimes biosocial factors of life.

The following chapter gives the methodology that this study applied. The methods of data collection and the analysis criteria, as well as fieldwork experiences, are discussed in detail in the next chapter. The sections therein are a testament to empirical examinations of the extent to which biology and medicine determine and are increasingly changing and creating new ways of thinking about citizenship.

## **Chapter four**

### **Methodology**

#### **4.0 Introduction**

The aim of this research is to examine the extent to which HIV's medicalisation among schoolteachers in Zambia leads them to acquire therapeutic citizenship status, and what implications this status might have for national development. To achieve the study's overall aim, semi-structured interviews with HIV positive teachers were conducted in the Western and Southern provinces of Zambia. Participants were purposively recruited based on their status, gender, and rural or urban locality.

This chapter discusses the methodological approaches that the study utilised. It shows how and why a qualitative method of semi-structured interviewing, accompanied by descriptive statistics, was chosen to answer the core research question, and what specific qualitative approach was taken. Both epistemological and methodological issues are jointly addressed within some sections. Furthermore, a methodological account is given of considerations prior to and during the work, in particular of ethics and consent. The chapter sets out why specific methods were used, and how the data was collected, analysed and presented.

The chapter is divided into three sections. In the first section, a general case for qualitative methods is made, and then philosophical aspects of this qualitative approach are stated and justified. The second part of the chapter gives the procedural details of what was done, when and where, before, during and after the research. This part involves discussion around the study setting, participant recruitment, ethics, data collection criteria, transcription, coding and analysis. The third section is concerned with interviewee-researcher power relations and positionality, and this includes the researcher's insider-outsider position. Lastly, a summary of this chapter is drawn up.

Let us start in the section that follows by making a brief case for the choice of qualitative rather than quantitative research approaches for this thesis.

#### **4.1 The case for qualitative methods**

Most texts on research point to two strategies in social studies: quantitative and qualitative. Since this study focuses on participant representations of social practices and physiological realities, a qualitative approach that addresses people's meaning-making strategies is appropriate. The thesis also applies some descriptive statistics to parts of its data. The thesis's emphasis on quantification of what participants say about their lives, and on the meanings of those representations, represents distinctive features of how data is collected, presented and analysed in quantitative and qualitative research (Bryman, 2016). However, the thesis's research questions and objectives are primarily pursued through its qualitative work.

Since ART is increasing longevity and health, it is now particularly important for the research focus to shift towards more qualitative (rather than quantitative) empirical explorations, as well as conceptual accounts, in order to describe in depth and understand how people living on medication are finding the meanings of their chronic health condition. Quantitative research around HIV gives morbidities (death and illness rates and their causes), ART success and adherence rates, and QoL index scores, but not a richer and more complex picture of living with HIV, health and illness. However, assessing the level of a population's health in relation to HIV cannot be satisfactorily done without qualitatively considering the economic, political, social and psychological meanings and effects of living with such a disease, a lifelong chronic condition that requires daily medication (Wahlberg and Rose, 2015:61). With the above justification in mind, this study is qualitative, as it empirically engages with Zambian teachers' representations of their experiences of HIV. Thus, building on the integrated theoretical framework elucidated in the prior chapters, the therapeutic citizenship of HIV positive teachers in Zambia is explored here using a predominantly qualitative approach.

The section that follows situates the study in a broader discussion of philosophical paradigms. However, the ontological and epistemological arguments made in the next passages are about qualitative research specifically.

#### **4.2 Philosophical reflections**

The two sections that follow set out the ontological as well as epistemological situation of this qualitative research. The research design applied here is shaped by the priority

given to the shared experiences of participants (Charmaz, 2006). Interviewees' accounts in this thesis are the linchpin upon which the development of a theory that is open, operational, relational, variational, elaborative, categorical and unpredicted can be made. That is why this study's ontological stance relates to notions of 'being', valuing ART experiences as socially constructed (as supported by Scott, 2003), while the epistemological position is grounded in studying 'experience' through language.

#### *4.2.1 Ontology: a constructionist approach to therapeutic citizenship*

Studies in social sciences are confronted with questions of how knowledge generation can be affected by the nature of the social phenomena being studied, and by participant and researcher biases. These questions include queries about the research, and researchers as themselves social phenomena affecting the research. The nature of this research, like all social research, included some elements of researcher effects, both on the conceptual framing and, through personal values, on the empirical work. In this study, care was taken to minimise the extent to which my behaviour, beliefs and values affected the interpretation or categorisation of being and related elements as understood and represented by participants (Willig, 2013). However, the main ontological framework adopted here involves understanding the interactive nature of social entities in research processes.

With the above in mind, this study's constructionist ontological positioning is founded on examining both individual and shared understandings of the world. What makes objectivism fall short as a position to be applied here is that to draw on meaning, it requires the researcher's direct involvement in the process of observing or investigating objects or subjects (Bryman, 2016: 693); for this position, self-report, as in semi-structured interviews, provides no knowledge of anything other than the self-report itself. Objectivists assume a transparent access to knowledge unaffected by the ethical values, individual differences and social biases that inflect both discourse and practice – but these factors are acknowledged by constructivism as part of knowledge production and understanding (Burr, 2015:159).

Social constructionism helps in understanding what influences people's personal or shared reality, such as biomedical relations. For example, earlier therapeutic citizenship research's Côte d'Ivoire context focused on treatment rationing and either pilot or

experimental treatment (Lock and Nguyen, 2018). In this research, the interest was in the culture created around ART in a continuous process of reconstruction and internalisation of communal norms through language, power, and the biological and social variability of living with HIV. Hence, constructionism was used, due among other things to its feature of allowing the building of themes from findings – that is, driven by what participants said was the meaning of their social world based on their own lived experiences.

Because the construction and extraction of meanings is continuous and dependent on social actors' fashioning of world realities, the ways in which participants relate with others to create reality (Bottomley et al., 2000) appear within the research itself. Hence, participants in this study are in a way co-authors of the outcomes of the research process and negotiators of the produced forms of knowledge.

Despite the use of constructionism in this study, it is important to acknowledge its weaknesses, one being the danger that the strong constructionist approach treats ideas as more important than the material conditions that shape actions and situations. The social constructionist approach employed here, as opposed to objectivism, is based on the way that living with HIV is constructed socially. However, it is a minimal or 'weak' social constructionism (Willig, 2013), because there are strong elements of material reality around HIV: health is not entirely socially constructed, but physiologically based. For example, and in relation to the topic of this thesis, people with low CD4 counts cannot get better through linguistic foregrounding – they require ART; yet stigmatising language, or the language of 'AIDS victim' or 'HIV infection', can materially harm them. Language matters, but it is not the only thing that matters in the HIV field, because we cannot normalise HIV using positive language. We cannot even stop stigma, for instance, by renarrating HIV in ways that get rid of the social problems that give rise to it, which have their own realities beyond language. Therefore, the approach to HIV realities presented in this study can be seen as involving a modified, and not full, version of social constructionism, which suggests that human realities are malleable and changeable, but that language and other social phenomena have strong limits in their effects (Cresswell and Poth, 2017).

This study's minimal social constructionist approach does approach reality through language, to which it gives strong significance. It was of interest here to foreground what participants understood (interpretivism), and to see their lived ART experiences as a social construction operating through language and power (Smith, 2013).

A minimal social constructionism, as invoked here, is able to explore how the reality of life on ART is socially as well as medically and physiologically shaped, and how representations are also historically located within biosocial HIV discourse.

Consequently, my analysis of the findings in the thesis did not simply take interviewees' accounts at face value, because social constructionism suggests that language is both a result of and itself an agent in the social construction of realities, so that it needs attention in itself as a relatively autonomous field of effect and action.

An approach drawing on objectivism and positivism was utilised. Positivist hypothesis-testing often assumes the hypotheses are about objective reality. But hypotheses may be about subjective phenomena, or constructions. For example, the prevalence and effects of current cultural constructions of HIV as 'chronic' and 'liveable' can be tested by hypotheses. Moreover, the thesis does not make firm conclusions about such hypotheses or assume that the data only means one thing. So, the ontology is again constructionism – but a 'weak' constructionism, because of the stability of material factors.

Let us now turn to a discussion of some key epistemological considerations that impact on the thesis.

#### *4.2.2 Epistemological position of this study*

What is considered knowledge – let alone desirable and valuable knowledge – determines how one thinks a study should be done, and therefore determines collection and analysis techniques. In this regard, positivism and interpretivism are two broad epistemological strands in the generation of appropriate knowledge (Willig, 2013).

Positivism sets out the use of natural sciences-oriented methods in the study of social reality, and also demonstrates a strong link between theory and research. However, positivism has shortcomings; for example, in the social sciences, many phenomena are quite difficult to investigate via discrete hypotheses which lead to empirical research

with measurable outcomes supporting or not supporting the hypothesis – which is what positivism involves (Cresswell and Poth, 2017).

In contrast, interpretivism is concerned with how people subjectively comprehend and make meaning from various forms of social phenomena, and it involves researchers themselves doing similar meaning-making and acknowledging the subjective aspects of that process (Willig, 2013). Interpretivists also recognise and respect the differences between people and social groups that generate some of these subjective meanings. For example, in this study, participants' reaction to what is already known – especially medically, such as being undetectable and having a low viral load – was of interest, but one cannot get entirely objective knowledge when studying social worlds as represented by people. Being 'undetectable' and having 'low viral load' may be understood differently by doctors, let alone by patients, as well as having different meanings within the different contexts of their lives – different meanings for women and men, for instance. So more generally, the participants' wider understanding of what these medical categories mean, as well as their relaying of the categories themselves, is what is of importance in this thesis.

Interpretivist epistemology is often criticised for making research practice ambiguous by generating knowledge through techniques that do not address predictivity, and therefore gaining knowledge that has no predictive value (Bryman, 2016:26–28). Furthermore, interpretivists face uncertainty, because they use methods that do not aim for complete or fully coherent data analysis or a single conclusion. However, although social reality is partly subjective, in this study the reported ART experiences have to be understood as not only subjective but also having a strong relation to outside objective realities. Epistemologically, this is a 'weak' social constructionism, which is also this study's ontological position (Willig, 2016). In addition, the knowledge produced enabled the researcher to learn something, due to the fact that participants who might be considered HIV patients or service users were also HIV experts (Whyte, 2015) who through lived experience had knowledge that I was not aware of, as well as knowledge not covered in the existing literature.

It was easy, with more qualification, to be convinced of the value of the accounts given by these participants, because knowledge was generated not only from how they

represented and perceived individual phenomena, but more broadly through their representations of and deductions from what they said was the whole of their lived reality. In this regard, interpretivist epistemology allowed for some relationship between *what* participants said about their HIV experiences and *how* they were living their lives on ART. What mattered in this approach was not just knowing something or representing it, but also representations of participants' full understandings of their experiences. The above suggests that interpretivism allows a kind of holism that gives weight to the truth(s) of what is represented.

This research therefore adopts the framework of constructionism alongside interpretivism, as described by Bryman (2016). The link between the two exists largely in language for this thesis, because a) constructionism happens largely symbolically, and b) meanings are filtered through language. Constructionism does not suggest that truthful meanings can be obtained, as interpretivist positions may do. Weak interpretivism was deployed because interviews are not only meaning, but at times also evidence. Therefore, language is usually attended to in this thesis in relation to what it means (interpretivism), how means and what it does (constructionism), but also in relation to what, more transparently and simply, it says (the 'weak' objectivist element of 'weak' constructionism). This philosophical standpoint of the research helped me deduce how the positionality of the self, and relations with others, are created around some phenomena through language and other forms of interactional representations.

From the above, there are at least four issues to bear in mind. First, weak social constructionism as an ontology has relations with both objectivism and subjectivism, and the thesis acknowledges the powerful objective realities, especially physiological realities, with which participants lived. Second, these ontological approaches all have implications for methodology, suggesting a limited interpretivism and some elements of positivism. Also, it is not objectivism, but how to generate predictive knowledge, that is more important for the thesis's ontology, because it is not assumed in this research that knowledge is truth or that knowledge accurately reflects an objectively existing world. Third, social constructionism involves both the existence of powerful social rather than 'objective' (for example, medical) 'facts' (consistent with positivism) and the effectiveness of language, itself a social fact (Durkheim, 1982). Fourth, interpretivism involves knowledge as search-based and conducted with participants – hence, certainly

not positivist – and can contradict social constructionism. For instance, phenomenological investigations are interpretivist but not social constructionist. These points bring us to the study design, discussed in the next section.

### **4.3 Study design**

This study employed a broadly descriptive design for fieldwork, which involved semi-structured interviews to access current representations of living on ART and with HIV in Zambia.

The choice of a descriptive qualitative design was rooted in the need to elicit detailed and wide-ranging data about the little-investigated and little-understood effects, across people's lives, of living long-term with HIV and ART in the global South, specifically in the context of maintaining professional employment at the same time.

This descriptive process was achieved by being non-judgemental and non-interventionist in obtaining data, and being as comprehensive and close to participant representations as possible in data analysis, which started with a micro-level thematic analysis (Braun and Clarke, 2013; Ritchie and Lewis, 2003; Bryman, 2016). For example, to enrich interviews' descriptive capacity, an open-ended style of questions was used, as opposed to the use of a predetermined checklist of questions.

This form of design has methodological flaws, and has been criticised widely. One key drawback of fieldwork interviews that follow a descriptive path is the excessive danger of a later analytic focus on 'procedure and criteria', which can be too heavily addressed to a micro level so that larger structures are neglected (Creswell and Poth, 2017). But responses in this study included material related to, and indeed explicit participant perspectives on, higher-level structural and social phenomena that called for a higher-level discursive element of analysis – which can itself broadly be characterised as descriptive.

Another limitation of a descriptive framework is that pure description is often argued to be impossible in qualitative research, especially within analysis. Moreover, by adopting an interpretivist framework, a researcher explicitly commits himself or herself to something more subjective and interactive than a descriptive analysis, even at the

micro-level of thematic analysis, which is closest to the data – and perhaps also in interviewing.

In addition, the importance of tapping into a variety of views of and for the participants' and researcher's meaning construction theoretically and empirically works against a purely descriptive process or analysis. Neuman (1997:68) identifies some relevant advantages of such a variety of description; among them is that it enables the researcher to assess whether specific manifestations are simply a general issue or a local trend. In this sense, my task in this thesis was to induce and deduce from the data what others made of their social world while on ART, in ways that included but also went beyond description.

Based on the above insights, although the research described here is close to the descriptive framework, it did not follow a purely descriptive design. It was theoretically informed from the start. Even the interviews were not entirely based on eliciting purely descriptive data unshaped by prior work: they were semi-structured, and some of that structure was theoretically derived; and they went beyond just singular 'parts', aiming also to capture and explain the 'wholes' of issues explored in the study, again as theoretically understood. The research was also theoretically informed in its interpretation. For example, chapter five, which appears to be the most descriptive of the findings chapters, is nevertheless partly shaped thematically by prior research.

The following sections deal with the procedures used in conducting the research: preparation, data collection, data preparation and data analysis.

#### **4.4 Procedure**

The research procedure started with the application for ethical clearance, seeking permission from gatekeepers, making recruitment plans, deciding on the study setting, selecting the sample, constructing interview questions, conducting semi-structured interviews, data transcription, and using NVivo and other methods to conduct three levels of analysis. All are discussed in the sections below.

#### *4.4.1 Ethics and consent issues*

I acknowledged and followed the University of East London's code of practice in research. Given that this research involved human participants, approval before commencing fieldwork was mandatory. Gaining approval involved submitting an application to the university's research ethics committee. The following supporting documents were submitted with the application form: risk assessment, participant information sheets (including easy-read where relevant), consent forms (including easy-read where relevant), recruitment advertisement, interview schedule guide, evidence of gatekeeper approval, as well as a certificate of completion of the ethics and integrity research module (refer to appendices one, two, four, five, 11 and 12).

The assessment form identified risks related to the research, all of which were cleared by the ethics committee. The anticipated risks were more about anxiety and fatigue during the interview for participants than physical risks such as the safety standards of the buildings or houses where interviews were to be held. These non-physical but mental risks were addressed by making sure that interviews were open-ended – participants were free to stop at any time, or to take breaks. Participants who were uneasy during the interview process or required further information would be referred to professional counsellors and advice services with which I had good contacts – for instance, non-governmental organisations (NGOs) such as the Anti-AIDS Teachers Association of Zambia (AATAZ), the Heal Project, and the People Living with HIV Network. Additionally, post-interview discussions were held, during which participants were given the opportunity to converse about anything that had been triggered as result of participating in the study. Contacts with the researcher and supervisor for follow-up if necessary were made available.

Another identified risk was that interviewees as well as gatekeepers might require monetary or other material compensation for being part of the study. The researcher and some gatekeepers were at risk; thus, participants were informed beforehand and asked to confirm in writing that they were aware that there was no remuneration for being part of the study. However, the study was presented as one that might be interesting and useful, both personally and more broadly, and participants' transport expenses were fully and generously covered by me, without any offer of extra recompense.

Even though information sheets and consent forms were distributed to participants to read before the interview, I went through consent again at the start of each interview. This was done to assure confidentiality and anonymity for participants, factors which were maintained throughout the study analysis and will be maintained in intended publications, in compliance with all aspects of the University of East London's data protection policy (see appendix eight).

Although participation in this study was on a voluntary basis, when more participants showed willingness than my intended sample size, I stopped announcing the recruitment of participants to various schools and community health organisations. The volunteers recruited but not interviewed were told that they would be contacted for any future projects, as the number had been reached and resources were too limited for more interviews.

An archiving request for all collected materials was made, ethics committee permission was granted to keep the data in this way, and archive consent was clearly asked for and obtained from participants.

With regard to the translation of materials, which was addressed in the ethics application, participants in this study were teachers who had been trained in and used English (Zambia's official language) as a medium of communication to deliver lessons. Accordingly, they had a good command and comprehension of both spoken and written English. With the above in mind, there was no need for translation.

However, during fieldwork and procedurally, I had issues with the consent forms, which required participants to sign and indicate their names. Some participants found this process to be in contradiction with the information sheet, as they thought that writing their names down meant that anonymity or confidentiality would no longer be maintained. To handle this challenge, I allowed them to add their initials as opposed to their full names, since what is important for consent forms is understanding and approval, clearly shown by each participant, rather than the specific name.

#### *4.4.2 Contacting gatekeepers and organisations, and making appointments*

The procedure of ethical approval described above also covered the recruitment of participants by seeking written permission from gatekeepers. The letters announcing the study were circulated via email to gatekeepers such as heads of schools, district education officers and NGO officials, who then advertised the recruitment to their colleagues. Additionally, written correspondence was sent by email attachment to relevant members of my social networks, who delivered paper copies of introductory letters about the study to five school managers. However, these procedures were not very effective, as participants in schools did not respond to notifications that came through their superiors.

As part of the recruitment process and the ethical clearance requirement, permission from gatekeepers at research sites in Zambia was sought before commencement of this study. An advert in the form of a memo was made and emailed to Zambia, where it was circulated to eight heads of school (three urban and five rural). Only seven participants out of the 41 were recruited through gatekeepers; 34 were recruited through support group contacts and personal snowballing. Finding, approaching and recruiting the targeted sample was made possible through community health support groups for people living with HIV. The use of such social networks was of the most help in enlisting participants who were teachers and HIV positive. It was easier to recruit participants through personal snowballing in rural areas of the western province than urban areas of the southern province.

As a way of safeguarding myself as I travelled from one province or area to another – even the furthest-flung rural areas – to follow participants, a colleague always knew of my whereabouts. She was aware of the locations and times of all my appointments with interviewees, and was under instructions to contact relevant authorities if I did not confirm the completion of a set of appointments by the evening of each given day while in the field.

Challenges with some support group and education gatekeepers were encountered. For their help in recruiting some participants, large amounts of money as payment were demanded from me. After some discussions about the lack of full payments in this study, they accepted a token of gratitude for their help.

Although appointments with interviewees were made in advance, some interviews were organised at very short notice. Timing was also challenging. In the rural Western province, participants had to wait for me to finish interviewing their colleagues before their time came. However, during the interviews, I was not limited as to time; I continued as long as participants wished, without rushing them through the discussion. The resultant sense of researcher availability made participants very relaxed, and this was seen in the long pauses between responses made by interviewees, and the patience I tried to show as the researcher.

#### *4.4.3 Recruitment: plan B and the involvement of HIV negative teachers*

There was a plan B regarding recruitment. I made specific ethical provision for a possible HIV negative group of teachers within the sample within ethics approval application, by highlighting that in the event that the planned number of HIV positive teachers was not met due to the secrecy and sensitivity that surrounded the subject, then teachers who were not HIV positive but were willing to share their perspectives on the topic would be recruited.

Though the plan was a legitimate second sampling possibility, since all teachers in Zambia are affected by the epidemic, partly because of the widespread effects HIV has within the general population, and more particularly because of the epidemic's strong effects within the teaching and pupil population, it was not needed, as enough HIV positive teachers were recruited.

Nonetheless, 10 interviews with HIV negative teachers were done. I hope to analyse this data sets in parallel with the data considered in this thesis for a future journal article. Some of the issues (see chapter five) that were raised by HIV negative and positive teachers, when comparatively analysed, showed some discrepancies and inconsistencies between their accounts.

#### *4.4.4 Piloting study instruments*

Prior to commencement of fieldwork, a pilot was done. A total of four HIV positive individuals were recruited in the pilot. These individuals comprised two males and two females, of whom three were working for local government and one was a nurse.

Although the pilot was aimed at testing the adequacy of the research instruments as well as at checking how to use the voice recorder, it consequently helped me to estimate the length of an interview per participant. This piloting gave me an idea of how many participants I would be able to interview in a given day.

The language used in the interview guide was also tested during the pilot. One of the pilot participants had difficulties with understanding English, even though he worked for the council. These English-language comprehension difficulties encouraged my resolve to focus on teachers who fully understood English. It was also at the pilot stage that I noticed that the order of the interview schedule was not necessarily going to be that of the semi-structured face-to-face interviews.

Additionally, it was during the piloting of research instruments that this study's logistical issues were assessed. For example, interviewing participants in their homes was preferred by those involved in the pilot interviews. This flexible choice to follow recruited participants to their homes worked well in the actual process of the research, as many of them appeared more comfortable taking part in the study in their residence as opposed to their workplace, i.e. the school.

#### **4.5 Study setting and sample size**

As earlier indicated, this study is on Zambian teachers who are living with HIV. Why Zambia, and why HIV positive teachers? Zambia was used here because the country is part of the sub-Saharan region, which has the highest rate of people living with HIV and on ART. Also, Zambia represents about 4% of the world's people receiving ART (UNAIDS, 2015). The justification for working in Zambia is therefore around the difficulties of HIV citizenship and the development implications of a sizeable but largely managed HIV epidemic in a low- and middle-income country such as Zambia – issues which have been investigated only to a limited degree in scholarly debates. Additionally, one of the motivations for completing the study in Zambia is that I am a Zambian national, brought up, educated and living and working within the country. I have a good basic knowledge and understanding of the country and to some degree of the HIV epidemic's nature and history within it, as well as of the research sites - thus the ease with which I the fieldwork was done. My existing lecturing relationship with UNZA also facilitated fieldwork arrangements.

Zambian teachers as the target population of this study constituted an interesting but also complex group with diverse needs and privileges. With regard to working with teachers, although there were conceptual justifications in terms of this professional group's importance for development yet its precarious position within the professions and the middle classes, interest in this sample also drew from teachers being a risk group which was hit hard by the HIV pandemic in the 1990s and mid-2000 due to their enjoyment of a level of social status, mobility, and school deployment away from spouses (Kelly, 2000; Carmody, 2004). In addition, my own background, my degree in education and my experience teaching teachers at UNZA, made me familiar with this professional group.

Teachers who participated in this study were from two Zambian provinces: an urban area in the Southern province, and a rural area in the Western province. The selection of urban and rural sites was based on the interest of comparing and contrasting the effects of locality on health outcomes and the management of chronic conditions. The choice of the two provinces was justified by their having the highest HIV/AIDS prevalence rates among teachers in the country (MoE, 2012; ZDHS, 2015). The choice of these regions also had to do with the common languages used in these areas, in which the researcher has high proficiency. Below is the map of Zambia that shows the two research sites - with locations shaded with dots.

Figure 4.1: Map of Zambia showing the sites of research (Western and Southern provinces)



To achieve the aims of this study, both purposive and convenience sampling were used to select respondents. The selection of participants was on the basis that they were on HIV treatment, were healthy enough to respond to some questions, were teachers who were either HIV positive, were Zambian by citizenship, were fluent in English, and resided in either an urban or a rural setting.

The tabulation of the sampled population is as follows: 41 HIV positive teachers (21 males and 20 females) aged between 25 and 55 who were from both urban and rural localities. Participants were also selected on the basis of their being in work and living at home but not physically frail. It is important to note that the demographic categories – gender, age, teaching years, qualifications and location – were all collected at the end of the interview, so that these categories were not foregrounded to participants as

significant for the research, at a time when I had no means of knowing their significance, if any.

The sampling strategy aimed to provide exploratory contrasts between ages, genders and places of residence, within a sample whose shared characteristics included being a teacher and being HIV positive. Since treatment is now initiated at the point of diagnosis or in some rural places in Zambia to all those whose CD4 counts fall below 200, participants were living on ARV medication or its imminent onset, and were therefore all within the frame of therapeutic citizenship.

Location was a factor in the recruitment process, as it allowed me to evaluate the extent to which social bonds and resource availability differed in rural and urban locations. Age served to a large extent as a proxy for sampling people from different diagnosis and treatment generations. Gender was a key focus for the recruitment, as demonstrated in chapter five, which shows that men and women experience this chronic health conditions differently.

The rationale behind the number of informants was that detailed individual accounts matter more in qualitative research than a large quantity of participants. The aim was to create a dataset that would allow comparison of responses across locations, ages and genders through a reasonably sized sample, and that would also allow for enough detailed analysis to elucidate specific issues overall (Cresswell, 2007:126) around therapeutic citizenship. The inclusion of 41 participants in this research offered a sample large and diverse enough to allow the relevance and transfer, if not generalisability, of results (Lincoln and Guba, 1985).

As earlier stated, seven potential participants were approached and agreed to be recruited but were never interviewed. Some of the reasons for this were the difficulty of contact and arranging meetings, failure to turn up, demands for remuneration, and my exceeding the expected sample size. There were no withdrawals from the study during the course of an interview. However, after working with six of the participants, I recruited more respondents outside of my already established links through snowballing from these interviewed participants.

#### *4.5.1 Constructing and conducting semi-structured interview questions*

The ways in which research begins is with constructing suitable questions. The nature and focus of the questions in this study were a guide for my interest in the subject (refer to appendix five). The dialogue between researcher and participants delved into how things were going, what challenges and successes were being faced, and how things could be better. The interest in remaining close to the real experiences of informants required that questions be framed openly, along the lines of: what did you do? How did you do it? Why? When was that? How did that make you feel? The ‘what’ question was an opener to expressions of experiences by participants. If the responses were in the affirmative, ‘how’, ‘why’ and ‘when’ questions then followed. This probing approach was in pursuit of exploring contradictions, inconsistencies and apparently ‘irrational’ responses. Thus, a ‘yes’ or ‘no’ answer would be followed by ‘how’ as well as ‘why’, in order to follow the flow of interviewees’ own talk. However, there were responses that appeared contradictory. To deal with this inconsistency in answers, a more flexible approach was used, and this included going to another point of discussion and coming back to the issue that had been contradictorily addressed by the interviewee, asking for more elaboration, but this time around using different wording.

Questions in this research were open-ended but not too broad (see appendix five)

Questions moved from the general to the specific, so as to strengthen arguments with not only information but also examples.

Semi-structured interviews were used in this study. The semi-structured interviews employed here were flexible in that they allowed me to alter the sequence and even the phraseology of questions (Ritchie and Lewis, 2003:110). The interview format that this study utilised was one-to-one and each interview lasted for a period of 20–50 minutes, usually without a break, although participants were free to take a break at any time. The semi-structured interviews followed a question guide, although the order of asking questions was not important (Patton, 2002). The interview schedule did not try to be exactly the same for each participant, but aimed to follow what each participant talked about. The interviews were conducted in a distraction-free place that participants preferred.

The interviews were generally cordial. Most participants seemed to become comfortable after assurances of privacy and my not asking for personal information other than demographics or general details such as gender, age and years of service, which I asked at the end in most interviews. The starting question (see appendix five for the actual questions) created rapport by being informal, setting an atmosphere that would be friendly for both the researcher and the participants. Questions on, for example, how participants described themselves were related to identity; those on HIV coping strategies were broadly thought to be likely to relate to governmentality; and chronicity was linked to questions about the period from HIV diagnosis through to ART commencement. However, I was aware that these initial theoretical interests of the thesis might find expression in many areas of participants' interviews.

The interviews also provided me with informal communication cues, which would have been impossible to obtain through a questionnaire. These cues allowed extra data to be incorporated to findings from the one-time interview with participants. Though these cues were not transcribed, they were in the field notes; which were helpful in relating well to findings around the dichotomy between HIV statuses as well as around competing (though sometimes overlapping) modes of being therapeutic citizens in participants' account.

Though suitable for this study, interviews are not without disadvantages, which might be logistical in nature. This may be the need for a secure place that is comfortable for the respondent, the time demanded for further probing of interesting arising areas, and the personality traits of the interviewee and researcher, which sometimes do not accord well with extended one-to-one talk about difficult issues with a stranger (Creswell, 2007). To address this latter issue, the pace of the interview was largely determined by the interviewees themselves. The researcher's role was to probe further on issues that required more explanation but not to probe beyond participants' willingness to respond. As a researcher, my role was to let the participants speak freely, to talk about their experiences with someone they were meeting for the first time. In order to do so, I showed attentiveness and concern about the issues participants were describing, and I probed for further details where possible, but without interrupting or pushing.

The last question allowed interviewees to talk about anything else not yet mentioned in the interview. This was like a second interview within the first. The open question asked at the end of the interview in many ways allowed participants to interrogate and interrelate responses that had been given earlier. It gave the informants a chance to reflect, thereby (in)validating (most) ideas previously discussed and perhaps addressing topics not focused on in the interview structure.

Additionally, field notes were recorded in a diary which captured participants' interaction with the researcher and others. These notes also covered informal conversation on the HIV topic, in educational and other everyday settings.

The use of a Dictaphone as a voice recorder was declined by two informants, without my asking for reasons. Therefore, I had to take notes of what was said during and after the interview.

#### *4.5.2 Data transcription and coding*

Interview audio recordings were transcribed manually. The interviews were transcribed word for word. Paralinguistic features of the interviews that were transcribed included; degree of articulation, rhetorical pauses, lengthening as well as primary and secondary language accents (Edwards and Lampert, 2014). These features were selected because they set boundaries of the most central responses across themes and allowed isolation of brief segments of excerpts from conversations that were important in the three levels of analysis.

Poland (2016) argues that transcripts contain inherent bias that is associated with their being verbatim. The verbatim transcripts often focus on speakers' verbal signs to convey a conversation, which can be open to human errors such as language or misinterpretation of words, when careful consideration is not made during and after the transcription process.

These transcriptions were imported and saved as soft copies, both into NVivo and on a laptop that was password protected. As it has been stated in the ethics section above, all identifying information mentioned on the audio record was removed. The information

provided and transcribed remains confidential, in line with the existing University of East London's data protection policy and as mandated by law.

The transcripts were processed using NVivo Pro 12 for thematic coding and analysis. I read through and listened to the audios several times, during the coding, which involved clustering specific quotes with similar meanings in topics or categories. Each code housed a set of individual interview excerpts stored and compartmentalised in NVivo as drawn from different transcripts.

By coding the responses manually in NVivo, some of the transcript excerpts were coded to more than one category of themes. The repetition of the data under different codes set can be seen as reflecting the overlapping of key issues. Additionally, it is these extracts from some transcripts that have been quoted in the findings and to some extent merged in the discursive chapters as to support key themes in the analysis. Therefore, findings are accounted for and results presented separately from discussions of the process of analysis.

#### **4.6 Data analysis: a three-level approach**

Analysis in social research is often driven by the aim of developing, describing and interpreting meaning as opposed to determining causes (Cresswell and Poth, 2017). This research analyses fieldwork materials in an inductive, bottom-up way as well as analysing them in a more deductive, top-down way in relation to existing literature. The second part of this process both consolidated and challenged the initial theoretical analysis, providing potential new avenues of consideration. Both aspects of the interpretation operated through three levels of analysis, although prior theoretical considerations shaped the second two levels of analysis more than the first.

The first level of analysis was largely data-driven, although categories from prior HIV research were also drawn on. This level mainly involved descriptive accounts of the findings produced through preliminary thematic analysis. Some data were treated quantitatively in this initial discussion of findings (see chapter five) and considered the frequency of certain reported experiences and views among participants, around gender, age, time of diagnosis, period and experiences of being on ART, support sources, status

disclosure or lack of it, common phrases or words, coping strategies, and motivation for treatment.

The second level of analysis, in chapter six, involved thematic categories, which were determined by applying, concepts from the thesis's initial theoretical analysis, to the themes emerging from the data in chapter five. It was at this stage that ideas from discourse analysis were first called on in analysing the findings, specifically to identify and describe themes related to language and power. In chapter three, chronicity, governmentality and identity were reviewed conceptually. In chapter six, I took up these concepts analytically. They appeared within HIV positive teachers' accounts, as temporality, biomedicine, and sociality, a slightly different framework derived from second-level interview analysis. The evaluation of data involved remained thematic, even after moving to this second level of analysis (Braun and Clarke, 2006, 2012; Livholts and Tamboukou, 2015).

The third and final analytical level moved into examining therapeutic citizenship in relation to elements of language and power, again drawing on discourse analysis. Here, analysis again also involved a consideration of representations and control. Again, the data were thematically analysed by grouping similar issues deriving from chapter five and chapter six topics together in relation to the main research focus for this chapter.

It is important to note that the findings are not purely presented by theme, because in chapter five the reporting of results is done partly according to responses by interview question. While this does limit the cross-interview level of thematic analysis, analysis did include work at that cross-interview level. The justification for keeping a question-framed approach to the analysis was that the existing literature did not report people's experiences based on the categories these questions addressed, and I wanted this analysis to be able to clearly address specific omissions from prior research that I had identified as well as demonstrating new themes generated by the participants. Doing the thematic analysis to some extent within the categories set up by the questions allowed me to do that.

#### *4.6.1 Thematic analysis*

Thematic analysis of data was used in this study. This was primarily because it is a highly flexible framework of analysis (Braun and Clarke, 2006:78). Since one of the interests of this research was to identify patterns of meaning, thematic analysis as a method was the most appropriate approach for this task, because it describes and organises the data set in extensive detail, and even captures different topical issues beyond the study objectives, allowing for a complex and multi-levelled approach. Often data patterns in thematic analysis are identified through a bottom-up (inductive) and/or top-down (deductive) approach (Frith and Gleeson, 2004). Due to the integrative theoretical framework, a combination of inductive and deductive approaches was used, to allow the themes to be determined by the data itself as well as by my initial theoretical framework.

Entering material into NVivo in categories, I started to do thematic analysis; initial coding was part of the first level of this analysis. Analysis started out very descriptively and broadly; it then became more narrowly thematically organised. This progress raises again the important point that even the initial thematic analysis was not purely inductive but was a dialogue between bottom-up and top-down approaches, which was how the findings were generated and data was managed.

By allowing a broad range of perspectives on the data, thematic enquiry is flawed for 'higher-phase' analysis, because it potentially makes precision in guideline for such analysis difficult if not impossible (Patton, 2002). That is, the wide range of possibilities for the shape of lower-order analyses make it difficult to specify how those lower-order analyses can be developed further. Another, related disadvantage of this method is that in the process of deciding what is useful in the data, there is a high probability that the researcher might face challenges in knowing which data from the fieldwork is worthy of analysis, and conversely, where to stop in attending to and analysing the data.

In spite of its potential disadvantages, thematic analysis was used in this research because of its strengths, especially when it is integrated with attention to discursive elements of the data that could also be treated thematically. The conceptual frame developed at the beginning of thesis and used here, as earlier stated, was an attempt to work with existing research results, and also to allow the transfer of claims, which could

help the external legitimisation and evaluation of new insights on the topic (Lincoln and Guba, 1988).

By examining the words and expressions of participants through codes and search features in NVivo, themes were identified through a combined bottom-up and top-down approach to participants' representations which also, especially in the second and third levels of analysis attended to features of language and power within those representations. However, the move from thematic analysis to thematic analysis informed by discourse analysis was mainly related to the thesis's interest in specific theoretical framings relevant to HIV citizenship., which took a larger part in the analysis in chapter six and chapter seven. Hence the analysis was mainly thematic, supported by some discourse analysis-influenced thematic work done through an examination of specific aspects of language and expressions of power within the data. Foucauldian ideas about biopower, in particular, were used to move from chapter five five's predominately thematic analysis to more discursively oriented thematic analyses of participants' ART representations mapped more theoretically, in chapter six and seven. This leads to the next section, which explains how elements drawn from discourse analysis were used within this research.

#### *4.6.2 Elements of discourse analysis: deploying a Foucauldian approach*

To focus on discourse involves treating language as a topic, and form of action, rhetorically organised and constructive (Bryman, 2008:501). Interest in discourse analysis in this study drew from Foucauldian discourse analysis (Foucault, 2008). This because the discursively oriented thematic examination of the findings in chapter six and seven especially involved an attention to the (re)construction of objects, subjects, realities, society and identity framed around HIV practices and institutions, in and through language; and also, an attention to the power relations of such (re)constructing. This discursively inflected thematic analysis resonated with the study's conceptual framework, which addresses power relations, most obviously around governmentality; and with the study's ontological and epistemological position which this study posits, emphasises, like this discursively oriented analytic approach, how people's relations to lived realities of for example identity, are constructed through language (Squire, Andrews and Tamboukou, 2013).

My drawing on discourse analysis here could not usefully have employed other forms of discourse analysis, as such as critical discourse analysis, which do not so clearly address the place of power relations in for example biomedicine. Here, focus was put upon what power structures could be identified as constitutive of what was being said by participants, thereby legitimating some explanations and expressions whilst rendering others less powerful.

Attention to language led to the analysis drawing on discourse analysis as opposed to conversation analysis. Since discourse analysis is constructionist, it places emphasis on realities' relations with language, something that conversation analysis does not do (Wooffitt, 2005). Discourse analysis does not supply the researcher with methodological instructions on how to proceed with interpretations of data. However, the discursive element of this research explored the subtle ways participants created their own symbolism of HIV biomedicine. The complexities of reported ART experiences made discourse analysis appropriate for understanding the historical and contemporary layers of stories about living with HIV, across such categories as age, gender, professional life and locality.

During interviews, the informant is the key subject of discourse. The data are analysed discursively by paying particular attention to the representations presented by the interviewee. In this regard, interviewer statements or questions in the exchange are not captured or assessed here, as this would be standard in conversation analysis as opposed to discourse analysis, though it could also be feasible within a discourse analysis. However, I have focused for this thesis only on participants' thematic and discursive representations of their lives with HIV and ART – the representations which, my research question suggests, have been neglected. Although interviewer questions were fully captured in the transcripts, they are not shown in the presentation of findings, except for within excerpts from interviewee speech. Not standardly including quotes from the interviewer in the thesis makes my emphasis on participants' own themes and discourses much easier. But this does not imply that researcher positionality and participant-researcher interaction have not been considered as part of this research.

#### **4.7 Place of the researcher: insider-outsider positions in dialogue**

Details about the personal issues of researchers are important in that they are central to the conduct of research and in efforts to capture issues around situated knowledge (Letherby, 2013). The researcher is the instrument of data collection, presentation, and interpretation of empirical and theoretical variables. Therefore, a brief account of the researcher's life and history is given here, so as to have a sense of his place in this study.

To begin with, this study was conducted by an HIV negative researcher who was not a schoolteacher. This implies that I have no personal experience of being a schoolteacher in either a rural or an urban Zambian setting. Since I am not HIV positive, I have no first-hand experience of being on ART and living with the virus. For instance, if I were a schoolteacher on ART, the way in which the question of Zambian therapeutic citizenship was addressed might have been different and maybe would have included autobiography. In some ways, not being a teacher and not having HIV rendered me an outsider. My role in the interview process was more that of a spectator than a full participant (Goldkul, 2012). My interest was in absorbing the viewpoints and developing an understanding by connecting and relating parts to wholes (Neuman, 2000).

I have not done research in the field of HIV/AIDS before. However, I have some considerable experience of lecturing, including on social research and of doing social science research on other topics, which helped me throughout this research. Based on my experience in the disciplines of education and politics, it was possible to export some of my skills from the fields where I have conducted research into this study. In addition, I have general experience of and interest in teaching, albeit in higher education. The responsibilities that come with teaching make it a thrilling profession, at least for me, particularly because of the opportunity teachers have to impact on the lives of learners with different backgrounds.

A combination of factors explains the decision to research this topic. One of them relates to personal experiences of training to be a teacher in Zambia. In spite of my training as a secondary schoolteacher, I decided to pursue the career of university lecturer in teacher training – a job I hold at the University of Zambia in a school of education. My position as lecturer was significant for professional networking, for

instance in receiving feedback on this work and the recruitment of potential participants. However, I retain an interest in secondary teaching, and in factors that affect the lives of secondary school teachers. Though not an insider', I am therefore not completely an outsider in relation to this topic.

HIV is significant for me because I consider it as a serious and a once fatal illness surrounding me in my country. I know and have seen the way in which it affected some people I knew, growing up – and the big change represented by people gaining access to ART and living longer, when many others had died. This understanding of HIV, though common to many people in Zambia and other countries with high-prevalence epidemics – give me something of insider status (Greene, 2014).

My native origins are in Zambia, one of the lower-income countries in SSA. My relation to the country is based on its being my place of birth, and I was educated within it before I left for postgraduate studies abroad. The social context of linguistic exchanges in informal conversations using Zambia's local languages during my fieldwork let me be seen as one of the locals – an equal – so that on this account I was mainly considered an insider, despite coming from UNZA and UEL as a university researcher.

The class struggle in my society is punctuated by hopelessness, especially for people like my parents, who had no education and basic literacy. Within issues of class, some participants expressed how much they thought I was from a privileged class, especially to be studying abroad.

My positionality as a researcher in this study was however also tied to my role of exploring and interpreting 'meaning' as it appeared in accounts and representations of participants. This research from another perspective can be seen as an advocacy project, because it was done from and with passion, with a secondary but explicit aim of at some point generating research that will be of use for people living with HIV and their allies. In the next section I address power relation issues between researcher and participants more specifically.

#### **4.8 Power relationships: vulnerability, sensitivity and interviewer-interviewee dynamics**

Managing power relations between the interviewee and interviewer can be vexing. The researcher-participant relationship was complex, for example, when handling emotions, not influencing responses or questions, and the researcher being patient for answers. These are issues that ought to be anticipated when dealing with what is often considered a sensitive topic and vulnerable research subjects.

Sensitivity and vulnerability issues still exist and play a part in HIV – although in different ways in Zambia than for other countries such as the UK (BSA, 2002). In Zambia, HIV is part of people's lives and not very sensitive. These issues are reduced in this research on Zambia by careful attention to power relations. The sensitivity and vulnerability aspects were considered within ethics, as indicated in some sections above, as being fundamental in this research.

Sensitivity was around concerns of data usage and sharing in relation to self-disclosure of HIV status by participants to the researcher. The potential for sensitive data was about how personal information was to be managed especially where I reviewed the transcripts and found some personal information that was underestimated as sensitive. The handling of sensitive information is acknowledged in some sections at the start of this chapter and was acknowledged in ethics application guidelines. I stated in the applications that I was not asking about personal details which researchers identify as ethically sensitive – for example mental health issues. In interviews where sensitive information was given by participants without being asked, I took a thorough review of data, to break links between data and identifying individual information.

HIV/AIDS in Africa is often considered a sensitive area of research (Iwelunmor et al., 2017:276). But in this study the topic seemed less sensitive, due to what Hyden (2013:226) refers to as trustworthy 'relational circumstances' between interviewer and participants. Contextual circumstances, for instance, the researcher's orientation towards positioning the participants as the experts, and views held by informants around preferences about research physical spaces, which were given preference in the research placed the researcher in at times a more subordinated position.

This research potentially had vulnerable individuals. It was an HIV status, in the context of stigma and limited or no information as well as material resources that rendered some participants vulnerable. Since the majority of participants found living on ART hard and were medically reliant, these participants were deemed as ‘vulnerable’. However, using my professional networks with NOGS and as mentioned earlier, referrals were made available on any vulnerability issues that could have arose.

Additionally, some participants expressed their freedom and agency in the interaction by declining to answer questions that they thought they could not, and deferring giving responses to some questions in the interview process. This may be understood to signify informants’ freedom in giving responses without being rushed by the interviewer about what and when responses were given.

This power distribution may have reduced sensitivity but still made some issues sensitive. The researcher’s privilege to ask about anything (despite participants being free to decline to answer) played a role in shaping this research, whose process was deemed hard not only in recruitment but also in participants’ openness to speaking during the interviews. Also, the researcher was dependent on the individual interviewee’s willingness to give details on a topic which thus allowed the participants to assume a position of power. The ethical perspective of this study provided an entry point that committed to handling and showing appreciation for discussing HIV issues whilst acknowledging that the topic was culturally problematic and prohibited (Chapoto, and Jayne, 2005; Doyal 2016).

As a student researcher, my access to large resources compared to those many participants can be seen as a power issue. Thus, the hegemonic nature of interviews would have overall, despite my concerns to shift power to participants, swayed the researcher to be at the centre of the dialogue, with power held over informants. This dynamic was important for me to recognise but also to present as realistically as possible – not just because of my theoretical and advocacy standpoint, but because some participants may perhaps have thought I had solutions to their challenges which I did not possess.

#### **4.9 Chapter summary**

This chapter has discussed and justified the methodological approaches that were employed for this study. It has been noted that the analysis of meaning from a large data sample can be a subjective task in qualitative research. The possibilities and difficulties of deciding what to cite and what to leave out of the transcript were ameliorated by sticking to the research question and study objectives, although chapter five presents a largely data-driven, bottom-up, and as complete account as possible of the study findings. However, to avoid omissions of higher-level themes that might have an impact on research conclusions, links between emergent themes from findings and conceptual frames were examined, particularly in chapter six and seven.

The discussion given here covered the study's philosophical issues. It also covered procedures for selecting the sampled population, construction of questions, semi-structured in-depth interviewing, transcribing, and forms of analysing the data thematically. All these processes were shaped by the study's philosophical orientation, which was a primarily inductive thematic analytic methodology, accompanied by elements of a more deductive, theoretically driven approach and by discourse-analytic concepts that this study employed in higher-level analysis. The handling of power relations between the investigator and the participants is also explained.

This thesis's methodological approach adds to the debates on best research practices in fields that link citizenship and biomedicine. The methods used and described here helped to understand how participants' HIV identity around ART was constructed, the everyday chronicity of their lives, and the governing social and medical interaction in their communities.

Having addressed this research's methodological process here, in the next chapter I give a thematic qualitative presentation and analysis of the results from the initial thematic analysis.

## **Chapter five**

### **A qualitative thematic account of therapeutic citizenship: medical, psychosocial and material factors**

#### **5.0 Introduction**

Following the discussion of literature and methodology in previous chapters, here I discuss some of the key findings. These are selected based on the research questions, and rest upon a descriptive and analytical approach, in order to first outline and then offer detailed consideration of the principal fieldwork findings. Some participants are more quoted across the sample than others due to their articulation of themes and centrality of responses. The results show not only what HIV positive teachers know about health and illness, but also how they comprehend and cope with HIV. It also gives participants' everyday experiences – long and short term – of living on ART in relation to both self and others. Although the quotes from participants are based on emblematising themes, some are used as general responses that are not specific to describing a theme; these were useful for examining speech style and notions of language.

This chapter has been divided into six sections. The first section gives a description of the sample, while the second section presents participants' accounts of health and illness. The third section is concerned with the diagnosis and treatment periods of informants, with details about long- and short-term experiences of being on ART. The fourth section deals with issues around disclosure, acceptance and stigma, and the fifth addresses the school space and other work-related issues around HIV and ART for teachers. The sixth and last section offers a thematic map, as well as extended detail on some of emergent themes from the results. The following section starts by highlighting the context of the results in relation to methodology (outlined in chapter four).

#### **5.1 Situating the findings**

Therapeutic citizenship (Nguyen, 2005; Rhodes and Papparini, 2016; Passellen, 2014) can better be understood by engaging with people's perceptions and tapping into their life experiences. The findings here are a representation of qualitative data, that is, participants' stories of living with HIV and ART. The data here also includes a review of total years of being on ART, the frequency of mentions around key topics (which are

illustrative), and descriptive and statistical information about HIV-citizensed teachers in Zambia. Transcription of all interviews, word for word, was done by me and processed using NVivo Pro 12. This followed an inductive thematic analytic methodology, but one which recognised the construction of themes in language.

Through a thematic and discourse approach, individuals’ narratives of their experiences are presented here. This is presented through themes: some of the key issues that were reported by the sampled population. This coded and thematised way of presenting findings was suitable because it revealed the number of respondents who offered similar responses within the broader research sample. While presenting in this manner can be flawed, as it takes participant reactions in a reductive and generalised way (Hollway and Jefferson, 2013), this downside is mitigated against here by including extracts and mini-analyses of prominent quotes. These extracts are emblematic of overall ideas within the data across the demographics of participants.

Table 5.1 below gives the demographic characteristics of the sample, from which variables are presented and some bivariate relationships examined. This information was collected through information and consent forms that every participant completed immediately prior to their interview. The categories that were collected were as follows: gender, age, region of residence, level of qualifications attained, and years spent in teaching service; the diagnosis period was extracted from questions asked during the course of the interviews.

Table 5.1: Sample demographic information

Gender	Age			Location		Education			Teaching years			Diagnosis period	
	>20	>30	>40	Urban	Rural	Cert.	Dip.	Deg.	>1	>10	>20	Early	Late
<b>Male (n=21)</b>	2	9	10	12	9	2	16	3	6	10	5	5	16
<b>Female (n=20)</b>	0	8	12	8	12	0	20	0	7	6	7	12	8

From Table 5.1, there are several cross-cutting issues that can be noted around age, period of being on ART, teaching period, location (rural or urban), gender, and some level of education qualification. For example, the gender distribution was proportionally equal. Although some male teachers were reluctant and delayed showing an interest in

participating in this study, they had an extra representation of one, making the sample tabulation 21 males and 20 females. The majority of the female teachers in this study were teaching at primary and lower-level tiers of Zambia's education system, whereas several men recruited were from urban areas and were working at secondary schools, getting a higher salary with relative access to medical facilities.

The age of participants – not a consideration in recruitment – had a 93% concentration of both males and females in the range of 30–50. This age range raises a number of issues: when the HIV virus might have been contracted, how likely treatment was, and how much information had been available concerning treatment. Furthermore, the age breakdown speaks to the fact that some of these teachers had done their training at a younger age, judging by the number of years served. For instance, Sibeso, aged 55, had been teaching for 36 years; when we evaluate this we can see that she got into teaching at the age of 19. The number of teaching years was between a minimum of one year and maximum of 36 years – periods which had a bearing on how one lived and worked with HIV. This was because number of years served and age acted as proxies for time since becoming HIV positive and/or being diagnosed.

This is descriptive data which shows that more women than men had early diagnoses. Twelve out of 20 females had tested for HIV much earlier, compared with five of 21 males. Table 5.1 represents diagnosis period as a gendered aspect of the demographics. The variance between men's and women's diagnosis periods suggests that women went to test earlier after infection, without any signs of physical illness, whereas men waited until they were sick to be tested and treated. Also, women's being long-term survivors of the pandemic meant that they got tested and commenced on ART as a consequence of either spousal death or antenatal visits for would-be mothers; this discrepancy is discussed in detail later. As can be seen from Table 5.1, the years of teaching experience ranged from one to over 20. Most participants who had taught for more than 20 years talked of wanting to change their job from teaching, with six even discussing retirement after teaching for a long time.

When we consider the level of education of the participants, it is noticeable that all females in the sample were diploma holders, and that the lowest qualification of school teaching certificate was held by two males. The highest educational qualification of

degree was held by three males, all of whom were teaching in urban schools. Sixty per cent of females reported a desire to pursue the higher qualification of a degree. The majority of teachers with diplomas and those with certificates were in rural areas with few opportunities to advance their qualifications. Similarly, locality had a bearing on the gender distribution, with women clearly over-represented in rural areas.

A number of issues were identified in relation to health and illness in participants' accounts of their chronic HIV condition. To evaluate the level of comprehension, some questions aimed to start a dialogue based on broad representations of disease and well-being. In the section below, participants' opinions on the meaning of health and illness are contrasted.

## 5.2 Health and illness: participants' accounts in general

Multiple realities appear to inform participants' representations of disease and well-being. Interviewees' general definitions of health were broad, yet they could be consolidated into the four main categories outlined in the table below:

Table 5.2: Meanings of health

<b>Participants' understanding of health</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Emotional, social and mental wellness</b>	4	3	7
<b>Absence of physical discomfort and body pain</b>	5	10	15
<b>Being happy with self and society</b>	4	3	7
<b>Capability</b>	2	2	4

About 37% (15) of participants defined health as the absence of body pain and complications, whereas 10% (four) viewed health as the ability to conduct one's duties. Thus, public elements of health were twofold: lack of physical pain, and capability to function. Only 17% (seven) indicated that emotional, mental and social welfare issues were key aspects of their health. The majority commented that health was physiological. For example, in the extract below, health is described in relation to state of mind and body:

Lutangu (Female, 40): Health is the well-being of someone in all these angles, that is, emotionally, spiritually and socially. I would have mentioned the physical aspect but because when one's emotional aspect is

not good even the physical part is affected.

It was suggested that the invisible signs of disease did not relate to being ill. For instance, mental health issues largely remained outside of many informants' responses in relation to health and illness. The majority of participants suggested that health was about the body being well and not being on any form of medication.

The second part was concerned with participants' views of illness. Some felt that illness was when the body was in pain, while others considered it as the lack of mental, socio-economic, spiritual and cultural wellness. From the data, there was an association between health and illness; thus what stands out in Table 5.3 is a high concentration of responses describing illness in physiological terms.

Table 5.3: Meanings of illness

<b>Informants' views of illness</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Physical pain</b>	9	7	16
<b>Failure to carry out duties</b>	0	2	2
<b>Mental, spiritual and economic distress</b>	1	3	4
<b>Emotional instability</b>	8	1	9
<b>Being diseased</b>	3	5	7
<b>Unwholesome</b>	2	1	3

In Table 5.3 we can see that 16 people (39% of respondents) echoed the view that illness was about both physical (body) pain and emotional difficulties. A minority of informants (17%) indicated that illness was about having a named and well-known disease. Close inspection of the table shows that very few (10%) participants linked their illness to economic, mental and spiritual challenges. These categories were created in this way because the participants, being teachers, had a good but low income flow, and also interest in the categorisation was on psychosocial issues or beliefs of managing illnesses more generally. What is interesting about the data here is that illness was described more as a physiological issue than a mental condition. For instance, Mweetwa defined being ill in light of the body failing to function and not being 'normal':

Mweetwa (Male, 42): Illness is actually a state of health where things are not functioning normally. The body is supposed to function in a

normal way, but it is not, then I feel the mind is supposed to function normally but according to what society has perceived as to what this what is normal, if I go contrary to that, they will say I am ill. So, in simpler terms, illness is doing things that are against what society perceives to be normal.

More profound for this discussion of illness was the way in which Mweetwa in the quote above described illness as something that was socially determined and normalised. The dominant way of conveying illness was often contrasted with the majority of interviewees' own HIV condition, which was sometimes socially shaped. It is interesting to note in the extract above that society sets out what is 'normal', and it has to be attributed to the body and mind.

When asked if they considered themselves ill or healthy, the participants did not have a unanimous view. Thirty-six per cent (15) of the interviewees agreed that they were patients, whereas over half (21) disagreed that they were ill, with 12% (five) stating that they were not sure whether they were ill or healthy. What is interesting are the reasons that some informants, such as Sophia, gave in their consideration of being ill. Among them were the requirement to take a pill every day, and the knowledge that they had a virus in their bodies. In contrast, those who said they were not ill argued that they did not have any bodily discomfort for them to be called patients. In this regard, Pelekelo argued:

Pelekelo (Female, 37): I am not ill. I am normal. Someone who is not healthy will be constantly sick. Before taking the treatment, I used to fall sick very often. But before I started the medication I could not do anything because I felt sick. I am able to perform my duties, I do not complain, I'm feeling alright.

The majority of the participants disagreed with the label of 'patient' because they were physically strong, even though they continually acknowledged that they were on ART in defence against being ill. The most striking aspect across interviews was the manner in which informants repeatedly described themselves as 'normal' because they were able to conduct daily routines around teaching roles.

By contrast, responses on the meaning of health and illness in Tables 5.2 and 5.3 reveal some inconsistency on emotional wellness and/or emotional instability. For example, only four women believed that health was about emotional issues, whereas eight characterised illness as emotional instability.

Participants on the whole demonstrated a minimalist representation of illness and health by focusing on physiological notions of the concepts. Responses about not being ill did not signify ‘normalcy’, due to having ‘something in the body’, as stated by Nalu (female, 31). Only a small number of participants referred to the mental, social and economic nature of illness and health. The next part of the results was concerned with responses that related to the period between testing for HIV and starting ART.

### 5.3 From diagnosis to treatment

Diagnosis of any illness is conventionally followed by medical treatment. In the case of this study’s sample, the period between testing positive and treatment was often reported as being determined by the severity of symptoms. A close review of responses reveals that participants on the whole had contracted the virus much earlier than they became acutely ill. Table 5.4 illustrates the year of diagnosis based on gender, with the women in this sample generally diagnosed far earlier than the men.

Table 5.4: Year of positive HIV test

<b>Year of diagnosis</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>2003–2007</b>	12	5	17
<b>2008–2011</b>	4	3	7
<b>2012–2015</b>	4	11	15
<b>2016–</b>	0	2	2

The free ART provision was rolled out around 2004, and it appears that women were eager to test when the mortality rate was high from HIV-related illnesses, from around 2000 onwards (NAC, 2009). What we see in Table 5.4 is a reversal between genders: more women went to test for HIV in the early 2000s, whereas more men tested after 2010. It is apparent from this table that fewer men tested for HIV; hence the high HIV

death rates among males at the start of the new millennium (see chapter two for a mortality account and statistics).

Judging from the differences in testing early and late across genders, highlighted in Table 5.4, the gap between diagnosis and treatment between men and women was wide. Table 5.5 is quite revealing in several ways about the long period that men had between testing as HIV positive and starting treatment.

Table 5.5: Period between test and treatment

<b>Diagnosis to treatment (years)</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>0-1</b>	12	21	33
<b>2-4</b>	4	0	4
<b>5-8</b>	2	0	2
<b>9-12</b>	1	0	1
<b>12-</b>	1	0	1

Table 5.5 shows that the diagnosis-to-treatment gap represented in the female column points to a generation when many men died, and some women participants in this study were survivors. The data also shows that men were seeking medication when already sick; hence the same test-and-treat concentration of almost all men, regardless of year of diagnosis. However, there is something common in the data. Although they were participants who had immediate treatment after diagnosis, in Table 5.5, 29% of females and 100% of males started treatment because they were too sick (men) or due to prevention of mother-to-child transmission antenatal checks (women). This implied that there was sometimes a longer gap between testing and treatment for women, compared with men who tested and began treatment instantly (see appendix seven).

These results show a generational difference in diagnosis and treatment between men and women, assessed using a common year. For example, the number of females who tested for HIV in the sample was greater before 2010, whereas more males tested after 2010. Although several women in the sample got diagnosed much earlier, treatment was initiated later and in some cases after a decade, due to good physical health and high CD4 count; whereas the majority of males reported being put on ART instantly or at least within the same year of a positive HIV test, due to reported low CD4 counts at the time of diagnosis.

If we now turn to motivations for seeking treatment among the cohort of this study, results reveal that seeking HIV treatment as a consequence of physical illness was reported by 31 (76%); this was unanimously identified as prominent. Six participants started their HIV treatment without any physical symptoms of the disease. These were mainly females who got diagnosed due to either sickness of their spouse or pregnancy (see Table 5.6 for ratios). Motivations for treatment varied among men and women, and Table 5.6 shows some of the main variations.

Table 5.6: Reasons for starting ART

<b>Treatment motivation</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Physical health deterioration/low CD4 count</b>	13	18	31
<b>Death/sickness of spouse</b>	4	0	4
<b>Encouraged by relations</b>	1	1	2
<b>Self-driven</b>	1	0	1
<b>Pregnancy</b>	2	0	2
<b>Spouse's antenatal clinic visits</b>	0	2	2

From the table, it can be seen that by far the greatest reason for seeking treatment was a poor state of physical health, which was highly prevalent among male informants.

Although ART access is free, some respondents found it difficult to start treatment. In many discussions, it was not only the frailty of the body that gave the need for an HIV test, but also the death of a spouse, even after refusal to start treatment.

Furthermore, some responses indicated that adapting to ART could be inspired by other HIV positive people's medical success stories. Similarly, children were also mentioned as the reason for both commencing and adhering to treatment by 18 out of 20 women interviewed, as opposed to nine out of 21 men interviewed. Yet for several informants, children helped with adhering to ART, as they were reported to be caregivers in the treatment process. Participants' situations with ART commencement differed in the long and short term. The next section of the study deals with some pertinent interviewees' accounts of the events surrounding HIV treatment.

#### 5.4 Long- and short-term experiences of ART

There was evidence that ART had an influence on informants' lifestyles. There were some negative and positive comments about the complex challenges of being treated for HIV. Although each participant's view varied across space and time, the majority of participants mentioned experiences that were similar in many ways. The results obtained were mixed between long-term and short-term effects, in relation not only to ART but also to the impact of being HIV positive. The top half of Table 5.7 shows the short-term and the bottom half gives the frequency of mentions of long-term experiences across interviews.

Table 5.7: Positive and negative effects of ART

<b>Experiences of being on ART</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Nightmares</b>	4	2	6
<b>Memory loss</b>	4	2	6
<b>Body changes (weight gain, skin and fertility)</b>	2	1	19
<b>Moods</b>	3	2	5
<b>Increased appetite</b>	2	0	2
<b>Dizziness hours after taking pills</b>	10	7	17
<b>Daily frequency of dosage is hard</b>	6	2	8
<b>Schedule of taking and collecting drugs is hard</b>	1	5	6
<b>Improved physical health</b>	2	2	4
<b>Curtailed travelling (carrying medication is problematic)</b>	3	4	7

Within the findings there were positive and negative experiences, in both the short and long term. Health recovery was mentioned as long term but positive. What is profound in the results shown in Table 5.7 is that 41% (17 respondents) experienced some dizziness every day and right after taking the medicine, lasting for at least an hour. The dizziness was reported to be disruptive, as it meant a period of inactivity until their reaction to the medicine stabilised. Moola described the aftermath of daily dosage:

Moola (Male, 51): After taking the drugs I always feel dizzy for the next one hour, after taking one sleep. [...] When I take the drugs and I'm feeling dizzy, I chat with my wife to just unwind and forget about how I'm feeling.

Taking pills every day at the same time was considered problematic by at least 34% (14) of the respondents. This is rather a significant result, as it reflects that some participants found it hard to take a pill every day for as long as they lived, without any hope of a cure. Alongside the daily dosage was the issue of quarterly clinic appointments to refill medication, which was seen as a burden by some interviewees. Talking about this issue, one interviewee said:

Sikota (Male, 52): I find it challenging sometimes to go to the hospital every three months and taking a drug every day. If there could be a drug that can be taken every six months instead of every day.

It was surprising from the data to observe that six informants grappled with loss of memory, which they said was a side effect of ART. Some interviewees mentioned that they found it difficult to remember things – for example, when to take medicine, and forgetting to teach some aspects of their lesson plan as teachers. There were some negative comments about physiological changes due to ART. It was suggested by some participants that problems such as weight gain, erectile dysfunction, reduced libido and infertility were caused by HIV treatment. Indeed, Sitondo reflected on his bodily changes, stating:

Sitondo (Male, 42): There is one thing I have observed. [...] My erection has reduced. So I have been having a feeling that maybe it is related to the drug. Some have said yes, others say no, it's your weight.

Being HIV positive was said to have weakened relationships and reduced levels of intimacy among spouses, by both males and females. This was related to experiencing uncomfortable weight gain by over half of the participants, while Sitondo's story above outlines how his weight gain (supposedly from ART) led to erectile problems. It was also common among participants to believe that antisocial moods were associated with ART treatment side effects and were a long-term negative experience of being HIV positive.

The remark above demonstrates the lack of right and adequate information about ART's workings. Also, it shows the absence of individual attention or discussions with doctors or health personnel regarding medical advice for participants.

For a small number of respondents (six), starting ARVs was a reason for sleep difficulties, including nightmares and sweating, which were short term as they lasted from days to months. For example, Beenzu described her experiences at the start of ART:

Beenzu (Female, 46): I just got tested and was given medication and told about the side effects to expect. My experience in the first three days was bad because I was bedridden. [...] After a month, I started gaining my strength. The first month was difficult because I had a lot of side effects.

We can see a commonality in these findings from Table 5.7: at the start of medication, physical fragility got worse, and adherence was hard within the first days and before the regimen was stabilised. This suggests that time plays a role in the effects of ART on long-term and short-term medical outcomes. Both positive attributes of having the chance to live longer and overwhelmingly negative experiences of being HIV positive were reported.

### **5.5 Managing the effects of being HIV positive and living on ART**

Some negative experiences in participants' responses cited above surfaced in relation to how they managed to live with the virus and on ART. Some interviewees argued that it was through knowing about self-care techniques, while others held the view that social factors were useful in their quest for a healthy life. Table 5.8 shows the key responses around factors that shaped how most participants described their condition and its management.

Table 5.8: Strategies for dealing with HIV and ART

<b>Ways of adapting to ART</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N = 41)</b>
<b>Exercise</b>	2	0	2
<b>Diet</b>	6	4	10
<b>Keeping busy</b>	6	5	11
<b>Time factor (conscious)</b>	5	2	7
<b>Beliefs</b>	5	3	7
<b>Acceptance</b>	0	6	6

It was interesting to note in transcripts that 11 (27%) participants mentioned the issue of keeping themselves busy – for example, belonging to faith groups, which was discussed in relation to belief or religion as a form of strategy to overcome HIV challenges. When asked about how she mitigated some of the hardships caused by the treatment she was receiving, one participant stressed the importance of being active:

Nalu (Female, 31): Keeping self-busy and not focus or thinking of the bad part. I have to keep myself busy. Mostly it's teaching and talking to other people.

Twenty-nine per cent of participants agreed that physical exercise and eating nutritious food were important for immunity-boosting despite being on ART. However, few talked about being able to exercise or following a balanced diet. In Table 5.8, it can be seen that acceptance, both from others and from oneself, was significant in the management of HIV, especially after diagnosis.

When responding to how they handled any effects of being HIV positive and on ART, most interviewees reflected on the principal reasons for their desire for survival and to live a long life. When they were asked about their life motivation, the majority of participants' responses, as shown in Table 5.9, based this on aspects of relations with others (family and friends), occupational factors (teaching), educational advancement (going for further studies) and aspirations (desire for a better life in economic terms).

Table 5.9: Factors in adhering to ART

<b>Life motivation</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Helping others</b>	3	2	5
<b>Family/friends</b>	4	3	7
<b>Teaching/vocational aspirations</b>	9	3	12
<b>Associating with others</b>	3	2	5
<b>Desire for good life</b>	1	1	6
<b>Nature</b>	1	0	1
<b>Achievement of goals</b>	1	3	4

Twelve respondents spoke of their desire to achieve their career development in their lifetime as a primary motivation. However, it was interesting (due to relationality elements) to note that 12% of participants derived their life purpose from associating with others. The majority of interviewees spoke about their life motivations in very complex ways. Within their stories, they showed a complex need for self-development as well as making a significant contribution to the common good. Mwaka demonstrated this complexity around her life motivation when she said:

Mwaka (Female, 43): Aiming higher and having a good life. Especially in my studies, I am studying and wish to go further. I'm doing a degree in primary school teaching. Some people who are HIV positive say they cannot go for further studies because they might die any time and not finish this study. Sometime in the early years of medication I would think like that. This time around I do not think that way.

The statement by Mwaka above shows some of the fear that most interviews attached to their HIV condition when making life choices. The extract speaks to both a social and a self-imposed sense of shame and powerlessness when trying to achieve aspirations such as pursuing further education.

As it can be seen in Table 5.9, religious faith and social life (as a whole) shaped how five participants thought of their life motivation. It was clear that being HIV positive involved a lot of psychosocial issues that one needed to confront, and most of these

were concerned with relationships. The extent to which participants felt and acted with courage was described in terms of social relations, as Likando put it:

Likando (Male, 28): I was uplifted and encouraged to learn that I wasn't the only one who was on this kind of medication. When I first learnt about my status, I thought I would die soon. But when my family members and friends, those that had lived for a long time, told me that they have been on the treatment for many years, I realised I would also live long.

It can be seen in Likando's statement that self-identity among participants was at least partially informed by external social forces.

In the data, responses about motivations were based on self-representations which differed across interviews. Self-imaging was reported in the light of HIV treatment by 15 participants, who retained a sense of self as largely being shaped by their biomedical condition. However, six described and related their self-image primarily based on their professional life of teaching. Only 11 directly mirrored narratives of themselves through relationships to family, children and others. Of all the participants, only 25 spoke of their personality and hobbies when they described themselves, for example as being humble, forgiving and playing sports. Only one participant was not sure how to describe themselves.

What stands out in the above data is that representations of the self were equally shaped by external social forces and personal life conditions such as being a teacher and living with a chronic condition that required daily treatment. However, being a teacher was important to some, in spite of their HIV status. For instance, Pumulo described himself in terms of being a father as well as a teacher, without bringing his health issue into the picture.

Pumulo (Male, 48): Having a family motivates me greatly, it makes me so happy. I am a parent and a very happy husband, and of course finding myself in the teaching fraternity. I am a teacher currently

handling computer studies at junior level. It really makes me proud of myself.

Responses about self-descriptions led me to ask further questions about being and feeling different due to ART requirements. It was striking to note that the majority of participants agreed that they were different from others who were not HIV positive. Only 17 % of respondents said they were not different, but they gave reasons that would distinguish an HIV positive person as different.

Table 5.10 gives some of the prominent reasons and their frequencies of mention in responses about what contributed to being ‘unique’ for those who were HIV positive and on ART.

Table 5.10: Reasons for being and feeling different

<b>Cause of ‘difference’</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Daily medication</b>	3	7	10
<b>Self-comparison and stigma from others</b>	4	2	6
<b>Loneliness</b>	1	1	2
<b>Mindfulness of virus after diagnosis</b>	8	2	10
<b>Physiological changes</b>	6	3	9
<b>Not sure but believe are different from others and old self</b>	3	1	4

Participants demonstrated that one was different from his or her previous life before diagnosis, and not the same as an HIV negative person, because of the factors in the table and also the following: stigma, spousal abuse, self-awareness of having an incurable blood-borne virus, weak relationships and losing friendships, fear of ART side effects and death, extra care for a healthy life, as well as psychological changes associated with HIV status.

From the above, it can be noted that awareness of being HIV positive constantly came into the mind, and was mentioned by 10 (24%) participants as making them think they were different. Many informants described how having a virus in their body made them develop a sense of otherness, as reflected in the comments by Mweemba:

Mweemba (Male, 39): I feel different knowing that I am not leading a normal life. I know that there are some abnormalities in my life, so it makes me different. It is within me. A normal life is where I don't have to think at this particular time I have to take medication, I don't have to worry about taking alcohol, I don't have to worry. And of course, we are talking about the length of my life. Who knows what it would be if I was not in the state I am today. Talking of social life, one or two things I have refrained from. Beer drinking and just the way I interact with the outside. Of course, not to convey the message that this is my status. I have not told the general public my status.

These results reveal two divergent views. The first is that most of the interviewees tried not to see themselves in a different way from those who were HIV negative; second, they acknowledged that owing to ART their lives had a quite different approach from those who were not positive. In this regard, the findings suggest that factors that informants said were reasons for feeling and being different were related to biomedical and mental issues. Overall, it was this sense of being aware that one had a virus – ‘something in the body’ (in a previously cited comment from Nalu) – that impressed as the cause of uniqueness in relation to both one's former self and other people in one's communities, including in the school as a workplace.

## **5.6 Therapeutic hope and uncertainties**

Despite reported improvements in physical health after starting medication, the body in several accounts was regarded as vulnerable and limited. Overall, 22 (54%) respondents commented on medicinal uncertainty, which they said was the source of constant worry regarding treatment failure on one hand, and the sustainability of the government supply of the pills they were taking on the other.

Two thirds of interviewees (64%) were hopeful of continued improved physical health through ART. However, the majority of participants' preferred time for taking medication was at night, so as to avoid any possible disruption to routines by the side effects of ART on the body, which were reported to be unpredictable. It was suggested that taking pills at the end of the day was medically and socially convenient, as they

found it easier to remember, and could engage in daily interactions without the interference caused by medicine. For example, Emonda said:

Emonda (Female, 35): I have always avoided taking the medication during the day when I am working. At least whatever side effects that are there would happen while I am sleeping.

ART experiences reported by participants confirmed the distinction between hope and uncertainty. Some felt that the medication gave them hope, while others considered that the lack of cure was a concern and a source of anxieties whilst on ART. Thus, Nalu's comment below illustrates many responses that were contradictory but pointed to concealed ART hardships that were physiological and psychological experiences:

Nalu (Female, 31): Just that living with a virus every day is a challenge, I can't deny that again. Maybe I will contradict myself, but there are times, like I was saying, I can't say I am a normal person like the other person, I have got limits, what the other person can do, me I would say, if I do that maybe I would weaken my body. I have to keep my body like this, I have to keep my body like this.

The emphasis placed on the protection and preservation of the physical body to keep it 'like this' and be able to carry out daily routines was contradicted, for example, by reports of side effects from ART that damaged the liver over the period of time of taking the drug. Eight participants emphasised the importance of a cure, while 11 described the need to reduce the number of times they took the pill from daily to maybe weekly or monthly. There were suggestions by the same eight interviewees that they used non-prescribed herbal medicines without withdrawing from ART in the hope that they could one day be cured. Take for instance Mutukwa's story below about how he would remain on ART as long as there was no cure:

Mutukwa (Male, 39): The only thing I find challenging is the fact that I have to take my drugs for the rest of my life. And the fact that there is no cure for HIV. [...] It was difficult for me to accept. I could not imagine

myself or to the hospital for treatment and take medicine every day.

The taking of ARVs every day was far from being easy, and was more of a challenge than the worry of having a virus. Besides a cure, informants talked about improved dosage from taking the pill on a daily basis to maybe once in three months. For several participants, the absence of a cure could at least be mitigated by having drugs to be taken periodically rather than daily. It was reported that taking pills daily without any alternative was a burden. In this regard, consider Nandi, who said:

Nandi (Female, 54): Taking medicine is not an easy thing. If it was injectable I think it would be better for me. If we could be injected for a year, like it is done for family planning, and then go for the other year. Taking pills every single day is not easy. Sometimes I forget, especially when I'm out of my home. I should take medicine at 18:00 hours. It's already 18:00 hours and I am still here at work. So taking drugs every day is not easy, one needs to be disciplined. Wherever you go, you need to have the medicine in the bag. It is more like a demon we are worshipping.

Surveillance by medical practitioners was associated with some uncertainties around ART's workings. Twenty-two participants indicated that their primary concern was around two key but separate issues: treatment failure, and cuts in the supply of free drugs in the future owing to potential changes in policy.

Emonda (Female, 35): Only hope the government would not stop giving ARV drugs for free. I can imagine that if the drugs were not free, many will perish. To only depend on diet cannot work. [...] My worry is that should the government stop subsidising the ARVs our country's production levels will fall down. Almost every year we will be losing millions of teachers. I hope even the donors helping with supplying ART should continue, because without them we are doomed.

Interviewees reported uncertainties and worry when the media reported drug shortages at clinics. However, the majority of participants appreciated the government's role in the supply of drugs; all agreed that they were worried about the future supply of ART. Talking about this issue, Kalaluka said:

Kalaluka (Male, 49): When I hear on television that there is a short supply of the drugs I get sick psychologically. When I go for review and I am given for a month or two weeks, I get worried. Sometimes we hear rumours that the government will stop supplying the drugs. We get worried because we are surviving because of these drugs. When I stop taking Septrin, I get affected, what more when I stop taking ARVs because they are no longer being given.

The quote above reflects mental distress among participants, especially during drug rationing. Fears about buying the pills out of their income were a concern for many interviewees, as they noted that their current salaries could not cover all HIV treatment services in the absence of free access to treatment. Because most of them said they were unable to even afford nutritious food, paying for ARVs could be hard if not impossible. In the same vein, it was suggested that taking a pill on daily basis acted like a reminder that something was wrong with their bodies or that they were ill. One interviewee even described the treatment as enslaving due to the strict timetable for taking the drug:

Ngolwa (Male, 52): What binds me only is that I have to make sure that I have eaten before taking the medication. The timetable as well. There was some news where somebody was talking about the future medication where somebody will be given an injection maybe for a month. That can give us a lot of freedom. The only thing that enslaves us is at 20:30 hours I have to take the medicine.

The description above shows some frustration at what could be called 'pharmaceutical colonialism'. In connection to discussions around better dosage regimens, half of the interviewees talked about their fear of death. Fifteen (37%) interviewees said that they and their families always worried about dying due to HIV in spite of being on ART. Responses from about 50% of the participants showed that perceptions of ART's lesser

effectiveness drew from reports and stories of people who were living with HIV dying whilst on treatment. Perhaps this result reflected the limited medical understandings and substantiation of ART's functioning in the social element of information-sharing.

Together these results provide some insight into the contradiction between interviewees' knowledge of the workings of the medicine they were taking and its relation to death. It was apparent that one could die of HIV only if one did not adhere to ART and did not follow healthy a lifestyle. But fear of ART's failure in bodies was mentioned in relation to the need for a cure or reduced dosage by 60% of participants. Thus, the worry about taking drugs for life, without any hope for any non-daily curative drugs, caused mental health issues.

### **5.7 Confession: the challenge of stigma and seeking acceptance**

In accounts of the events surrounding disclosure, a range of responses were prompted, and these were divided between those for and against going public with their HIV positive status. Sixty-one per cent of interviewees said they had disclosed their status to family and friends only, and 10 participants (24%) reported not having disclosed that they had HIV to anybody apart from health personnel and me. The majority of those who had disclosed privately – that is, to family and friends – had done so involuntarily due to circumstances such as the birth of a child, sickness or marriage. It was striking to observe that only two (male and female) of the respondents were publicly open about their HIV status, and they had featured on the radio and in magazines to share their stories about being HIV positive teachers.

From the above statistics, disclosure was inevitable for the majority of participants due to ill health. Participants' accounts on the whole confirmed that revealing and concealing an HIV status had social and psychological implications. Commenting on disclosure, three participants stated that it was a basis to educate others, four said that it gave peace of mind, 16 believed that it was good for acceptance and support, and 10 participants spoke strongly against confession due to HIV stigma, with about five suggesting that health issues were a private matter and not a public concern. The majority of participants seemed to conform to the principal of involuntary disclosure.

It is clear from the findings that disclosure was a form of escape from having to take pills in secret at all times. However, it was taking a step to open up to others that was noted as more challenging. There was a strong association between disclosure, space and people. It was agreed by over 60% of interviewees that trust was key in opening up. For example, in the school set-up, unpredictable reactions from colleagues as well as learners were a concern for several participants. Over half of the participants who had disclosed privately spoke of the difficulty of opening up due to blame from others, which led to self-shame. It was noted that being HIV positive was about victimhood. Again, consider Mweetwa's comment:

Mweetwa (Male, 42): I realised that my family was not going to like it. I realised it was a disappointment. I can tell you that at some point I thought of committing suicide. [...] I was blamed, it has not been easy but when I started opening up I realised I was not the only victim of the same disease.

For some informants, letting others know about their ART was a breach of and embarrassment to their profession as a teacher. In contrast, being open about HIV status minimised some of the tension, but over a long period of time. Take the case of Mwaka, who had been on ART for more than 14 years:

Mwaka (Female, 43): I have just told myself that I can take the drug any time anyway. Even at work I am free to take my medicine, so I feel that has helped me. It wouldn't because I have friends at school who tell me that when I am with certain people I should try to hide when taking the drugs. I tell them that it is part of me and how many times am I going to hide? If I am in a group study in the same room, what would I do when it's time for my medication? Regardless of what people say, I'm free to take my medication.

Although Mwaka claimed to be comfortable taking her pills in public, a close look at her statement reveals that she was cognisant of the social forces around ART, how it affected and was shaped by social networks and was about others. However, being

accepted by others after diagnosis led to personal acceptance, which seemed to be a necessary precondition for disclosure:

Sitondo (Male, 42): I have accepted my condition [...] because it is psychological. If I don't disclose and people start knowing about it, I will would feel bad if I hear people talking about it. So when people talk about it when I have told them, then it does not become an issue. So it reduces its power on me. Actually, disclosure is a strategy. [...] What I have realised, like at our school here, most teachers are shy, they don't want to disclose, even when you meet at the hospital they will tell you to say 'you should not go and tell people that I am'. [...] But I have laboured also to encourage them to say the best strategy is disclosure, so what I can attest to is that even now there are people that still have that self-stigma. They think that they will be looked at negatively.

Sitondo's story shows some social and mental benefits of disclosure. Opening up was seen as empowering and a necessity for the majority of participants, as it was seen as some expression of acceptance by both oneself and those around one.

About half of the interviewees did not disclose voluntarily to family and peers. Over 60% of participants talked about being happy when with peers who were HIV positive like them, at clinics or anywhere, which made them feel they were not alone and inspired a sense of collectiveness. For example, disclosure was a source of hope and provided motivation through the testimonies of others for Mweetwa to stick with his treatment and accept his status:

Mweetwa (Male, 42): Some people started telling me, 'do you know that some of us discovered a long time ago but we are still alive'. [...] You know after learning that, somehow, I felt that some are cheating me, but I came to believe when we used to meet where we go and get drugs, 'even him is also taking the same drug, this one has been living for some time, I think I can also live'. Otherwise me I had reached a point where I was almost dying.

The majority of participants commented that it was easy to disclose to peers who were also living with HIV. Over 50% of participants found it hard to open up their status, even to close relations. Females were more willing to disclose than males, although two females had been instructed never to go public about their HIV status by their husbands, who themselves had not disclosed to their wives.

Confession of HIV for 60% of participants was discussed in the light of social implications rather than mental benefits. Ten per cent of participants felt that ART had reduced stigma due to improved physical health, while 30% still thought stigma was high and could even be experienced at hospitals from health personnel. In the next section, findings on patient-health personnel relations are presented.

### 5.8 Interactions with health personnel

The relationships between service users and providers in the HIV sector were described as positive by 10 and negative by seven informants. Also, there was an overlap of positive and negative experiences for at least eight participants. Sixteen did not mention any experiences with health personnel during drug refilling.

Table 5.11: Participants’ reported experiences with medical personnel at clinics

Positive	Negative
Welcoming conduct	Awkward social interactions, irrelevant questions, rude treatment, blame, pity
Group medical advice	Excessive precautions and differential treatment
Cordial partnership-building and paying close attention	Refusal or reluctance to provide care, unnecessary referrals, late diagnosis, treatment delays, insufficient support provision
Base for social networking and support	Lack of trust and confidentiality, little privacy due to limited one-to-one doctor appointments
Time for reporting health complications allowed	Limiting of ART pills’ apportionment

Eighteen participants reported positive interactions with medical personnel. The fundamental positive element was nurses’ ability to connect with and treat participants as a community. It was through this sense of a social network created by medical

personnel that participants described the clinic as a place where they had established new peer relations that had led to information-sharing through group medical advice sessions.

Attention to individual health problems given by health personnel and doctors was described as being positive. It was reported that participants were encouraged by clinic handlers to report any signs of health complications so that they could be treated or given attention by a medical doctor. This possibility to see a doctor for complaints regarding treatment was for most of these 18 participants a positive attribute.

The quarterly lessons on how to take care of oneself whilst on ART were seen as something remarkable. Lessons around, for example, what type of food to eat, how to live with partners who were HIV negative or positive, as well as encouragement to adhere to treatment for a normal life were articulated as something positive and supportive from and by health personnel.

Participants also spoke of the negative elements they had experienced. A minority argued that the clinic was an uncomfortable place that exposed one's HIV status to the public against one's will. The queues and long waiting times, and poor reception by health personnel, were also reported as negative factors by seven participants. The above statements reveal psychosocial and confidentiality concerns regarding service providers. The difficulties of interacting with health personnel and access to resources appeared more problematic for people who went to test for HIV when they were sick. David explained the tension between his clinic appointments and his job as a teacher:

Pumulo (Male, 48): Apart from the challenges I encounter when I go for check-ups, I feel that that I'm not given attention, because as a teacher I need to get my treatment and get back to my class and work. I am usually delayed at the clinic because of the procedures they have.

In relation to privacy and being served expeditiously, some participants indicated that stigma was prevalent from medical personnel, and was subtly exhibited by means of language tone and the uncooperative attitude with which nurses handled specific cases. This privacy issue prompted participants to register for their ART pill collection at

distant clinics where they were not known by locals. Some negative experiences by seven participants were associated with their profession and how they felt they needed special treatment since they were teachers. Talking about this issue, Sumbwa said:

Sumbwa (Male, 39): Sometimes I am bothered. Because when I go to get medication sometimes, I don't feel welcome at the health centre. Sometimes when I go to the health centre I get exposed to a lot of people, and some of the health practitioners do not understand me as a civil servant. This is because some of these people that give us medicine are just caregivers from the community. Sometimes they do not handle us very well. I get delayed by the volunteers because they do not understand that I need to get to work.

There were some derogatory terms in Sumbwa's remark that seemed to be induced by his profession. For example, when he said 'me as a civil servant' or 'just caregivers from the community', these sentiments showed classist representations in how the high-status participants presented themselves and the low status they accorded to health personnel.

In spite of all the reported hardships, none of the interviewees reported an issue with not accessing the medicine. The negative and positive categories covered above were mainly around social aspects of interactions and the level of effectiveness. From Table 5.11 we can see that it was limited medical knowledge and frustration about the bureaucracy of ART distribution that made services from health personnel ineffectual. However, some positive elements included having pills delivered at home, which brings us to the issue of support systems. In the section that follows, I look at the sources and forms of support, including expectations that this study's cohort alluded to.

### **5.9 Participants' personal, microsocial and meso-institutional support sources**

In the interview process, respondents were asked about the available forms of support structures for living with HIV and on ART, support here being the material, medical and psychosocial forms of help that participants received due to their HIV status. As can be seen in the data in Table 5.12, support bases were complex and depended on personal and social relations and one's available means for self-help – a category discussed later.

Social support (family and friends) for half of 31 (76%) informants was transformative, while for 10 participants support was regarded as either absent or very low.

Table 5.12: Frequencies of key sources of help

<b>Support sources</b>	<b>Women (n=20)</b>	<b>Men (n=21)</b>	<b>Total (N=41)</b>
<b>Family and friends</b>	12	19	31
<b>Government/donors</b>	9	8	17
<b>NGOs</b>	4	2	6
<b>Media</b>	1	1	2
<b>Church</b>	1	1	2
<b>None</b>	8	2	10

Views around support mainly surfaced in respect of family and friendship. The majority of the 31 respondents who commented on this issue noted that it was mainly messages of encouragement, and for 16 out of the 31 informants material assistance such as food was received. Among the 31, it was not entirely HIV positive family and friends who accounted for positive experiences such as being very supportive and accepting. As Nalu commented:

Nalu (Female, 31): I have this friend who helped nurse me after I gave birth through caesarean section. I don't have parents. She was on the bedside, so I just had to tell her that 'me I am like this'. But unfortunately, or lucky enough, she is also like that. So that is when she also opened up to me and said, 'even me, I am like this'. So that makes the two of us, then we keep each other. Since stigma is there in Zambia... so we decided to keep each other's secret. There is another friend of mine who is negative that is supportive. She supports, she says, 'it's not a death sentence, you still have a lot to achieve'.

The majority of participants stated that either friends' or family support – and this included spouses who were HIV negative – had helped them cope with their HIV condition in a positive way, while others had poor relationships with their families and attributed the lack of support from family to their poor health recovery. Seven females in the sample claimed that their divorces had been caused by revealing their status to

their husbands; only one male attributed his wife's decision to divorce him to his positive status, as she was tested negative.

The observation emerging from the theme of positive social support is that in the absence of family support, friends were mentioned as being supportive. For example, Mwangala described how family relationships were negative and friends were more supportive:

Mwangala (Female, 49): My family that knows that I am sick, [...] some keep away from me as if I am dented. It is not the same. Now, with my friends there is not much difference, because there are some friends of mine that I share information with, we share secrets and they know my status. We share information.

With only friends not family, and being acutely ill and a single widowed parent, Mwangala faced mental and physical health that became worse, even in the midst of her ART. It is important to note that friendship support was strongly reported by informants in rural areas due to absence of family, and in urban localities due to stigma. Family interaction after diagnosis was reported to decrease anxiety. But six informants who discussed not receiving any form of family support reported signs of depression, isolation and suicidal thoughts, particularly in their early stages of diagnosis. Perhaps relatedly, participants who had withdrawn at any time from taking ART medicine indicated limited or lack of any form of family support.

Mostly, those who had been married for a long time enjoyed high support even after the diagnosis of HIV in themselves and sometimes their spouses too. However, unmarried informants spoke of their worry and problems in finding a partner to support them socially, emotionally and even materially.

Participants were asked about the government support they had received, and 50% had great appreciation of the government's role in providing free ART access. The established government initiatives on HIV in Zambia appeared to have brought the state

and HIV positive people close together. Dependent but positive relationships between the state and patients were mentioned in some interviews, for example by Beenzu:

Beenzu (Female, 46): So somehow, we are dependent on the government. If the medicine is not there, I feel my life would be short and I might even start counting the hours.

Several participants also showed that they were aware of donors operating through government. Seventeen participants seemed to understand the national and international politics of HIV resource flows, as exemplified by Sitondo in the quote below:

Sitondo (Male, 42): I am very much sure that government on its own cannot manage us, we need donor aid. Because I have seen it with other drugs, when you go to the hospital you find that there are certain special drugs that are not there but ARVs are in continuous supply. Because of donor aid or maybe government has prioritised ART.

The medical help from the state, and the continued supply of HIV drugs when other medications ran out, made the case of support for ART peculiar. Although government efforts were appreciated, four interviewees clearly outlined that the state was slowly being drained of its resources by companies that supplied drugs. The point stressed by Sitondo above also points to the fact that African states, and Zambia in particular, may be becoming para-states due to their limited resource capacity to manufacture ART medicine locally and their extensive reliance on external help to serve their citizens.

Two participants spoke about how the procurement of drugs for their condition was making the state poor. Sumbwa also cast responsibility on external forces for the uncertain supply of ART, and placed a call on government to search for curative drugs:

Sumbwa (Male, 39): The cost of this medication is making Zambia poorer and poorer. Please make sure that the drugs that have been discovered and found to have curative properties for HIV are legalised and given to people that are HIV positive. The government of Zambia should work hard so that these drugs that are being tried and

tested should be made available as soon as possible, because the drug trial is taking too long.

The media was seen as a source of positive support by two participants, especially through testimonies of long-term survivors who were public about their HIV status. Much of the information gained from television and radio programmes on overcoming stigma and good ART adherence practices for better physical health was also reported to be helpful, as it was instructive about, for instance, having a balanced diet and the need for behavioural change, even through watching and listening to some disclosed positive individuals' stories. Lilato credited her transition to accepting her diagnosis to testimonies of other HIV positive individuals in the media:

Lilato (Female, 42): [I was] watching television and I saw a woman who is based in Zimbabwe. When I looked at that woman, I asked myself why I was trying to kill myself when there were people who were living positive and happy. I got inspired to live that way as well.

Three participants also observed that the media could be a source of misleading information. The media was considered negative when stories were spread about cure through prayer, and when advertisements for herbal medicines claiming to eliminate HIV from the body were shown, leading to withdrawals from ART. The media as a source of support was thus embroiled between messages of therapeutic hope and despair.

About 14% (six) of the participants talked extensively about the NGOs providing support services. Support groups for people living with HIV established by NGOs were recognised as beneficial in many respects, such as a feeling of being connected to each other, support, and learning what others were going through.

Participants also emphasised positive support from the Church. More females (12) than males (five) talked about the religious practice of going to church as an important aspect of their lives. Faith groups provided not only spiritual guidance but also social services, even to those who had not disclosed, and material support to two participants who were public about their status. Consider Emonda, who said the following:

Emonda (Female, 35): I have received support from church. I have received food supplements. They would get people who are positive and supplement their diet on a monthly basis. I also got an opportunity to get sponsored to do the teaching course through the church.

Thus, in between the state and the NGO, the support for HIV resource provision was the Church. Some interviewees reported, however, that the Church was not ideal for opening up, due to the moral tradition of religion. Sitondo said:

Sitondo (Male, 42): When someone is diagnosed with HIV, then that particular person is more of a sinner.

It was reported as uncomfortable for 50% of the participants to disclose their status at their places of worship. However, specific Churches, such as the Catholic and Seventh Day Adventist, were reported by two participants to be supportive through material provision and empowerment programmes for people that had disclosed their status at church.

Ten participants who spoke of not having support represented a category of self-support. Use of religious belief and personal earnings was reported by individuals who said they had no sources of support. Overall, these results legitimised the importance which people living with HIV attached to support that was psychosocial as well as medical. However, one's career could also have a specific bearing on one's health.

#### **5.10 Being HIV positive and interacting within the school space**

HIV positive teachers in this study revealed that workplace and colleagues' support was lacking, rendering the school a space that silenced AIDS-related discussions due to stigma among colleagues and learners. Some interviewees agreed that ART enabled them to be physically well enough to teach, but offering support to HIV positive learners was hard, as they (teachers) needed support themselves.

In accounts of living with HIV as teachers, the workplace in schools was described as having some power imbalance between those on ART and those who were not. Participants also discussed their HIV condition in connection with (non-)isolation in their professional lives. Table 5.13 illustrates the various levels of relationships and effects of structural interconnectedness.

Table 5.13: Groups of relationships and participants' positive and negative encounters

<b>Occupational interaction</b>	<b>Negative</b>	<b>Positive</b>
<b>Colleagues</b>	30	21
<b>School administrative support</b>	9	10
<b>Leadership roles/promotions</b>	4	26
<b>Programmes/policies</b>	9	8
<b>Parent-teacher associations</b>	2	4
<b>Pupils/teaching concerns</b>	2	28
<b>Locality</b>	4	3

When compared with 61% disclosure to family and friends, which includes colleagues at the workplace, the 30 participants' negative encounters can be associated with the reported restricted HIV disclosure in schools. However, confession to being on ART at the workplace seemed to be connected to particular encounters, such as seeking permission for a hospital appointment, and for the majority it was through meeting their colleagues at the hospital during drug refills. Consider Ngolwa's statement:

Ngolwa (Male, 52): There are two or three more people who know, though we don't talk about certain issues. I only discuss health issues with one.  
 [...] We are in the same department. At one time he wanted to be driven so that he could collect his drugs, and I gave him a lift. On the way back he asked me, 'do you know what this is?' I told him I know because I take the same. From there onwards we became close.

Seventy-three per cent (30 participants) indicated that they felt isolated from their colleagues. Twenty-one reported that they had good interactions with workmates – but exclusively with those who were HIV positive, as opposed to those who were negative.

When it came to discussing school policy on HIV/AIDS, nine interviewees indicated that their schools did have policies around HIV as well as anti-discrimination, but there was no focus on material help and empowerment activities for teachers living with HIV. Three participants stated that HIV programmes focused more on learners in schools than teachers. Three quarters of participants reported being aware of an HIV workplace policy in education but said it was ineffective and unimplemented, especially for teachers and other school workers.

Promotions and opportunities for further education in the sector emerged as an important issue. There were 26 (63.4%) participants who were in key positions besides teaching in their schools. These included principals, sports teachers, senior teachers' patrons and heads of department. It is clear from the table that over half of the HIV positive teachers in this study were involved in extra roles in administration as well as heading schools.

Over half of the informants had had a promotion. Some comments were made on the difficult and long period that it took to be elevated on merit and, it was thought, in light of being HIV positive. Additionally, those who were in top leadership positions expressed their concern about the latent stigma they encountered from their subordinates. However, the comment below shows that some participants were promoted on the basis of an HIV diagnosis disclosure:

Kalaluka (Male, 49): The bosses knew and at one time they even met us. So in the end they started giving us promotions. That is how I was also lucky to be given this position. We met several times, even in Zimba [District]. They would tell us not to feel intimidated. They told us they would not leave us promoting people. They told us we are part of them.

The extract above shows that an HIV identity is useful in securing promotions and making claims. By saying 'they' and 'us', Kalaluka points to the institutional significance of being on ART as an HIV positive teacher, which through disclosure helped him and others get promoted. For example, Nandi showed appreciation of ART,

which had enabled her to execute her duties as head teacher, and she had been using her position to encourage others to adhere to treatment:

Nandi (Female, 54): I have seen some people who disrupted taking the medicine and they died like animals. Being the head teacher is a testimony to me. I tell those that are positive to just take the drugs.

Similarly, being an ordinary teacher without any position whilst living with HIV was reported as empowering, and offered an opportunity to take up pastoral roles, especially on HIV/AIDS related issues, something that was reported as fulfilling. Discussing this issue, Moola said:

Moola (Male, 51): I organised the teachers who are living positively to get together. We went for training on the Care International concerning HIV and AIDS. We were told that if we tested positive, we had to access to treatment. We were told if we adhered to medication we would live much longer. That was quite satisfying. I became an active person and spoke for people living with HIV. I told the superiors that people that have HIV are able to work, they should not be sidelined. I had the privilege of sitting in the meetings with the DEBS [District Education Board Secretary] and people in the administration to speak concerning HIV positive teachers. During this time, I remember my health went down. But I continued speaking on behalf of HIV positive teachers, telling the administrators that HIV positive persons can also take up leadership positions.

Participants in positions of power in schools all agreed that their own HIV positive status had increased their efforts in campaigning for better work conditions for teachers living with HIV. The lack of material benefits on disclosure was a common view that most HIV positive teachers saw as a major reason for not coming out, unlike in other sectors such as the judiciary, which provided material support. Consider Nalu's comment:

Nalu (Female, 31): I don't think there are opportunities, maybe for my friend who is in the judiciary, not for teachers. Those, what they do, they get names of people who [are] positive and they would receive food vouchers – once in year. So most for them can open up. But now us teachers, there is nothing that we can open for, there is no encouragement; and once you open up, there will just be stigma, you find that other teachers will even start telling your pupils... 'your teacher is sick'.

Issues related to parent-teacher associations' (PTA) role in the fight against HIV were not particularly prominent in the interview data. PTA relations on HIV matters were very weak and mostly invisible in many schools. However, two participants stated that they had been stigmatised by some parents who had demanded that their children be taught by an HIV negative teacher. This encounter was described as discriminating and made them feel inferior as HIV positive teachers. Four interviewees reported good working relations with pupils' parents, in spite of their public disclosure of their status. Contrariwise, the hospital location and being seen collecting HIV drugs was embarrassing for some participants. For example, Milimo said:

Milimo (Male, 30): When I go to collect the drugs, I meet several people that have also come to collect the drugs. So, you find that people begin to talk and say, 'oh, so this one is also positive'. News about one being positive travels quickly. When one goes to collect medicine, they meet a lot of people that cannot keep it secret. Some wonder and say, 'even teachers, who are supposed to be role models, are HIV positive and have come to collect drugs'.

Twenty-eight (68%) interviewees spoke with concern of their learners and how at times being HIV positive conflicted with their teaching roles, compromising their efficiency whilst on ART and being carers for learners. Moreover, the majority of female (11) and some male (five) informants repeatedly stated their worries for learners whom they suspected had HIV but were not on ART. It was also reported by 70% of participants that most schools' hostile environment for disclosure appeared strongly in the stigma applied by teachers to HIV positive learners whose parents had disclosed the children's

status to school authorities. The gossip about such learners from teachers made HIV positive teachers themselves not want to open up about their own status at work. An informant explained it this way:

Emonda (Female, 35): There are times when parents would disclose the status of their children, and sometimes teachers would discuss the child's status and the fact that they are on treatment. That makes it hard for me to disclose my status to my fellow teachers for fear of being discriminated against. I have benefited because I disclosed my status. If I did not do it, people would treat me as a normal person.

Only six participants indicated that they had been able to be helpful and caring for learners who were HIV positive. Although interviewees mentioned that there were many HIV programmes for pupils by both government and NGOs, about eight participants described learners in the context of being more vulnerable and needing more support – although not getting it – than teachers who were HIV positive. This extended to four participants who noted that they could see learners with HIV symptoms – as teachers with HIV, it was easy to tell – but that it was hard to approach these learners or their parents about possible medical testing and treatment. For example, Mwaka said:

Mwaka (Female, 43): There are some boys and girls at my school who seem to be HIV positive but have not yet gone for this VCT [voluntary counselling and testing]. I am looking for ways and means of reaching out to them. We have clubs that talk about HIV and AIDS, but it is difficult for the kids to come out in the open and talk about what they go through. I'm wondering how the children will react if I tell them about HIV and to go for VCT. I do not know how to approach such children. I'm thinking I might get a negative response from the children and their parents that may cause problems. [...] I'm thinking of how best to help my learners and teachers that are living in denial.

The above comment shows the unpredictable reaction from both learners who seemed to have HIV and their parents. This was evidence of tension between work and life in the health context of an HIV positive teacher, as told in stories of the desire to help pupils who had a similar condition to their own. The tension was made even clearer by Lilato, who found teaching the curriculum-designated topic on HIV/AIDS difficult: it reminded her of the challenges she had experienced by being on ART and HIV positive:

Lilato (Female, 42): Sometimes when I go through the books and come across this topic, I ask myself if I should go ahead and teach it or leave it.

Over half of the 21 participants from rural areas indicated that school location played a role in terms of resource access as well as the collection of ARVs. Informants who were deployed to work in rural schools were more affected than those in urban areas. Four participants reported the difficulty of mobility to clinics for appointments.

Comparatively, three informants described teaching in an urban school as less stressful due to easy access to medical care and other services. In relation to location, it was observed, however, that support and social bonds were stronger in rural than urban schools, as observed in greater mentions of HIV community among eight rurally based participants.

Approximately 24 participants spoke of pressure from results-driven school systems. Increased workloads and the consequent long working hours were reported to have a negative impact on HIV positive teachers' motivation and effectiveness; this 'new normal' in teaching worked against their own 'normal' professional lives as teachers living with a chronic condition. However, learners' achievement and good teacher-pupil relationships were primary for over 50% of participants. For example, Mukela's HIV status did not stop him from pursuing high learning outcomes and pass rates in examinations:

Mukela (Male, 31): At work, usually what I feel good is when at the end of the year, when results come in, we analyse individual classes that we teach and looking at the pass percentage, like those we were teaching science, that makes me feel good about myself.

Being a teacher and on ART has everyday effects on teaching. Forty-five per cent of informants considered their status with a chronic health condition to be strongly related to not only their personal but also their professional life. For example, Njamba described how his treatment had a bearing on his teaching roles and set limits to the work he could do:

Njamba (Male, 37): I normally take my medicine around 21:00 hours. When I go for class in the morning, I feel dizzy. That affects the implementation of my lesson, especially if I have not eaten anything. When I get dizzy in the middle of my lesson, it affects me so much. When it comes to my work, I cannot say I am limited 100%, but I can say that I am somehow limited. I need to avoid working too much because that can suppress the immune system. I need to make sure that the work I do is within manageable range.

The above quote establishes how ART directly, and HIV more generally, coloured HIV positive teachers' interactions and the manner in which they taught in schools. The overall responses on the school space show indeed that it was often hostile for a teacher living with HIV. Interviewees argued that there was often an entanglement or contradiction between care for oneself and meeting learners' education needs.

Resource constraints were associated with an HIV health condition by 75% of participants. The income from teaching was situated between being too little and delayed. However, seven participants had used their teaching salaries to set up small businesses, which cushioned the deficit in their incomes. Over half of the participants indicated that teaching income helped them take care of their health by acquiring basic things such as food. However, some difficulties related to income were reported, and these included transport to hospital and work, maintaining a balanced diet, and housing, as noted in Nalu's statement:

Nalu (Female, 31): It has been difficult to maintain a balanced diet. You know life in Zambia has become difficult. Even when you are working, you find that your salary can't sustain you for a month. There will be a day when you won't have this, and you won't have. Like fruits

are expensive. Because at the hospital they tell you eat fruits and vegetables, but you can't afford to buy a fruit daily, even when you are teacher on a salary.

It was because of low pay that participants thought of pursuing further studies to improve their pay and lives by upgrading their educational qualifications. About 50% of participants noted that any attempt to do extra income-generating activities was hindered by their HIV positive status, the need to carry medicine, and the view that their bodies were too fragile for much work pressure.

All of the above income-related possibilities and problems were a direct consequence of being a teacher living on ART. Fear of further immunity compromises and insufficient resources from the teaching job put these participants in a position of simply working with what they earned, and for others reinvesting their incomes for more. The accounts above show the precarious socio-economic and complex livelihood requirements of being HIV positive for low-paid civil servants such as the participants in this study.

### **5.11 Discussion: contextualising ART experiences within wider HIV citizenship**

In this section, a listing of categories from the findings in the order of the thematic analysis is given, relating each to prior literature, primarily on people living with HIV, but also on teachers living with the condition.

#### *5.11.1 Effects of demographic factors on ART representations*

Accounts of ART experiences in the findings are gendered. This research's findings show higher negativity for women, with the majority reporting internalised stigma, and men reporting more medical challenges, as shown by Amin (2015), Camlin et al. (2018), Colvin (2019), Petersen et al. (2017) and Russell (2019). This study found that about 50% of all the women had sought treatment based on external triggers such as the death of a spouse, whilst 70% of the sampled men had waited until they were sick to be tested and commence ART, as research elsewhere (Fleming et al., 2016; Colvin, 2019; UNAIDS, 2016; Whyte, 2015) has shown. HIV literature on Zambia does not explicitly compare male and female ART adherence. However, survey statistics based on regions, as demonstrated by UNAIDS (2017) and Whiteside (2016:8–9), often do not capture why men are mostly not willing to test until they are sick, as found in Barnett and

Blaikie's (1992) study. This study found that most men did not seek medical help early due to a perceived lack of privacy and patriarchal cultural tendencies of wanting to seem strong at all times. The study also confirms previous studies on women being longer-term HIV survivors due to earlier testing and treatment (Campbell et al., 2012; Hegdahl et al., 2016; Murray et al., 2013; Whyte, 2015).

Generational differences in ART experiences are a key finding in this research. This study found that age and period of HIV diagnosis determined how participants lived on ART. Generational differences include e.g. that people who are diagnosed more recently and/or get treatment directly after diagnosis do better. There is more on generational differences in global North HIV research, such as Franklin et al. (2019). This is a new finding in global South contexts, partly because 'universal' ART access and access directly after treatment is much newer in those contexts, and in studies that focus on generational differences in terms of risk of HIV transmission, such as Street et al. (2016).

This study found too that locality and health are interconnected, as also shown by Collier and Ong (2006:3) and Marmot (2015). Locality appears to influence how ART is managed. In particular, participants in rural areas embraced peer support for ART adherence, more than those in urban areas. The research found that rural populations were more committed to treatment, even with inadequate resources, than urban dwellers. But the rural treatment literacy picture is mixed, because more rural than urban participants believed that HIV cure or better medication existed but was not for the poor, adding to findings by Squire (2007) and Kerry and Thom (2009) about HIV myths – which are widely covered in the literature – the possibility that rural people living with HIV are more susceptible to such myths.

#### *5.11.2 Participants' general perceptions of health and illness*

Participants described both health and illness from a physiological point of view, as other researchers have found (Annandale, 2015; Hughes in Collyer, 2015:448; Pallesen, 2014). This finding differs from Boorse (1977:542) and WHO (2015), who describe health not only as the absence of physical illness but as positive wellness – not a focus of these participant responses. However, the concern here is not with what health and illness are, but with how people living with HIV describe them. The majority of

participants focused on the body or physical ill health, having a virus, and daily medication with ART as the basis for considering themselves ill, as also reported by Flowers et al. (2012), Larsen (2016) and Stutterheim et al. (2017). The body was at the centre of ART's workings for most participants, as were processes of feeling or being different from others and one's old sense of self, as found by Young et al. (2019).

Mental health issues were not described as such by participants. However, feelings of anxiety and fear of death were frequently represented in relation to the early period of HIV diagnosis, and also after being on ART long term, adding to findings around the co-morbidity of HIV and mental health conditions in other studies (Adams et al., 2015; Halkitis et al., 2017; UNAIDS, 2018; Rooks-Peck et al., 2018). Close to 55% of the participants spoke of the mental health challenges of ART, as Chuah et al. (2017) and Dow et al. (2016) found. The majority of the men reported conditions such as depression – more than the women, partly perhaps because the majority of men worry alone and are not willing to discuss their HIV status with others, which turns their concerns into a mental health issue, as demonstrated by Uebelacke et al. (2015).

At the same time, in this study, social 'health' was a key aspect of living well with HIV and ART for most participants. The study found that ART effectiveness for 60% of the participants was not just about physiological and mental health but also either improved or disrupted social life, as Doyal (2016), Orza (2015) and White (2015) also showed. ART in this research was found to boost physical health, which then allowed participants to interact and attend gatherings, thus improving their social life. Also, ART's social life improvements can be associated with the already existing peer relationship base for those who are living with or affected by HIV. However, ART was disrupting social life when, for instance, the time to take medication overlapped with communal events, and when side effects were severe and visible, such as a rash or dizziness, which made it hard for participants to socialise. These findings on ART in the context of improving and/or disrupting social life are new, as they do not appear to be explicitly covered in most studies on HIV treatment.

### *5.11.3 Long- and short-term experiences of ART*

The present results have demonstrated that HIV as a chronic condition is not just felt as an illness but also experienced as a lifelong condition. This finding relates to the

description of chronic disease given by Cooper et al. (2013). HIV chronicity is also framed by the medical risks of withdrawing from ART and non-adherence. These risks are different from those with other chronic conditions where life may depend on medication, for example asthma or diabetes, because once a person stops or skips medication for a long period, the virus will become ART drug-resistant, as reported by three participants who withdrew from treatment only to resume on a different regimen, and as also found by Kim et al. (2017).

It was interesting to find that, despite the above, long-term issues around HIV were mainly psychosocial, and the short-term ones were more about the negative bodily effects of being on ART, as found by Nixon et al. (2017). It was the positive impact that ART had on the body that was seen as a positive consequence of adherence over time. In the literature, no empirical work exists that clearly contrasts ART's long-term and short-term impacts on HIV positive teachers in Zambia. However, other groups elsewhere report successfully conducting their day-to-day duties through ART, which enables functional health long term, as described by Lubkin (2016). This research found nevertheless that over 50% of participants did not find the notion of taking pills every day and long term 'normal', indicating the complexities of long-term adjustments to living with HIV and ART.

#### *5.11.4 Complex ways of dealing with HIV and living on ART*

HIV is a chronic and complex health condition with an ever-increasing caseload (Olmen et al., 2011; Uebelacke et al., 2015). Unsurprisingly perhaps, such a condition leads to ambiguities, even when treatment is available and successful. Although this study found reports of improvements in physical aspects of health from about 50% of the participants, it was clear that the burden of living with HIV and ART also had a negative impact, especially on the mental health of the 50% of study participants who found lifelong ART difficult to accept – who might also be the ones reporting improved health, as Locock and Ziebland (2015) also showed something similar.

It was also found by this study that gender affected people's reported adjustments to living with HIV and ART, since men were less accepting of their HIV status, and since material needs were secondary to medical needs when managing the effects of ART among women, particularly in rural areas in this study. Men, however, frequently

prioritised material over medical needs in their representations of ART. These findings are new, because they do not appear in any of the reviewed HIV research literature.

ART provision by the state was reported by 17 participants as a vital form of support, which brought appreciation and improved their relationship with the government. However, international donors and local and international NGOs were mentioned by 23 participants as key partners who sometimes overshadowed the role of the state in ART provision. Citizenship and its relation to medical and other claims will be explored further in chapter seven. These parallel relations to national and pharmaceutical citizenship in relation to HIV have not been elucidated in prior research, although the second aspect has been explored by Nguyen (2010), Robins (2008), and Rose and Novas (2005).

The technologies of governing HIV's long-term and short-term effects involve personal agency. This sense of agency was common for participants who had accepted ART around self-care practices and gaining microsocial (interpersonal relations) and macrosocietal (state welfare) support, as previous studies such as Pallesen (2014) and Stutterheim (2017) have demonstrated. By socialising and keeping active through such activities as gardening, going to church and exercising, participants were able to forget about their status and to access possibilities for self-normalisation through interaction, similar to the self-management techniques beyond HIV that McDonald et al. (2016) found in Australia. Results showed, however, that ART's long-term effects remained the basis of social otherness through the need to attend clinics defined as 'for the HIV positive' and to take pills daily, including in social situations. This finding is further explored in chapter six and in relation to other studies, especially around HIV, politics and nationhood.

#### *5.11.5 Ongoing uncertainty*

From the data, it can be noted that living on ART medication is full of uncertainties. Ongoing fluctuating symptoms such as dizziness, memory loss, skin rashes and even diarrhoea all contribute to the finding in HIV research that health and social disruptions are associated with HIV treatment side effects (Whyte, 2015; Bernays, 2016), except that the reported long-term dizziness experienced by the majority of participants after taking pills has not been fully addressed in studies such as Horter et al. (2017). Those ART

side effects reported and described in this research entail similarly long-term limitations and unforeseen complications.

The sustainability of the ART drug supply from the government was of concern and a source of anxiety for 22 participants. Perceived HIV treatment failures created uncertainties around ART, focused on claims of its damage to the liver, as Nixon et al. (2017) found – a perhaps surprising finding about the persistence of this concern, given the much-improved effects of ART.

This research found that bodies remained central in the articulation of HIV treatment uncertainties due to experiences of multiple physical impairments. This centrality appeared through participants articulating their own body as transformed and compromised by new medical forces that generated an uninvited need for care, which affected personal and public life, as a number of other researchers have found (Belgrave and Charmaz, 2015; Fassin, 2007; Locock et al., 2009; Nixon et al., 2017; Williams, 2015).

However, the reported recovery of physical health and social interaction improvements through ART continued to provide a sense of therapeutic hope among 27 participants. These findings seem to be consistent with other research which found that men on ART were pleased with their physical health as they were now able to work and take care of themselves and their families, and women similarly, with the addition that they were also hopeful of a cure because they could conduct household tasks, which gave them a sense of normalcy. Medical records and hospital checks on adherence are forms of surveillance systems which connect different spaces, periods and effects of ART on bodies. They were reported in ambiguous terms, as normalisation, and as a contradicting characterisation of the everyday aspects of living with HIV that produce an ART atmosphere, as also found by Ellis et al. (2013) in their study on affective atmospheres of surveillance.

The results here also show that when one is facing a life-threatening health condition, earlier aspirations as well as relationships become weakened, even when that condition becomes chronic and liveable. This happens through self-withdrawal from existing

social networks, even when participants are doing well, as has been shown by Campbell et al. (2005) and Goffman (1963).

#### *5.11.6 ART transforming but not removing stigma*

This study found that disclosure was not a one-time event, but a continuous process that was problematic. The theme of stigma and acceptance in the findings relates to issues around disclosure. There are two things that emerge on this topic. The first is that only seven participants who were not thereby seeking support disclosed voluntarily, indicating the situational process of disclosure. Second is the idea that those who feared to be stigmatised disclosed only involuntarily due to circumstances, and also that they had high levels of self-stigma through anticipation of negative disclosure outcomes. This finding on involuntary disclosure seems not to have been explored in previous studies, whereas the results on voluntary disclosure are similar to findings by Bond (2016) and Lyimo et al. (2013:102).

This study found that stigma in HIV care and treatment has only changed but has not been eradicated, as found by Bonnington et al. (2017). It found, though, that ART was said to have largely eliminated appearance factors associated with stigma by improving physical health.

Explicit questions about disclosure led to responses about the importance of opening up to family, friends and medical personnel, and factors that played into the decision to do so. This finding suggests that people who are HIV positive are now able to consider and predict successfully the effects of family disclosure, as shown by Camlin et al. (2017) and Sanden et al. (2016). In the absence of anticipated social acceptance, participants reported travelling to distant hospitals and always hiding their ART pills, as shown by Elwell's (2016) study. Responses on spousal disclosure were one-sided, as women but not men reported disclosing their HIV status to heterosexual partners, a finding which other studies (Bond, 2007; Henning and Khanna, 2016) do not mention.

Disclosure made it possible for participants to join HIV communities and created a sense of belonging, as described by Camlin et al. (2017:4–5). It also appeared that participants who were public about their HIV status had limited adherence difficulties, for instance having the possibility of getting reminders from others to take medication,

as found by Bernays et al. (2015) and Kim et al. (2017). Also, disclosure was a strategy for avoiding gossip and embarrassment and having peace of mind, as also shown by Bell et al. (2016) and Bond (2007, 2010). Self-isolation due to HIV shame was reported as a key reason for non-disclosure, depression and social withdrawal, similar to findings by Ho et al. (2017), Hutchinson and Dhairyawan (2018), Vincent et al. (2017) and Wong et al. (2017). These results are distinctive, because they show disclosure as a process and not a one-off event. It is this continuum of disclosure that makes participants anxious about their status, making it an internal and mental health issue that can either be beneficial or be associated with a lack of self-confidence and acceptance of living on ART.

The majority of participants described poor interactions with health workers during ART drug refills as a stigma issue that starts in hospitals – a striking finding at this point in the epidemic.

#### *5.11.7 Quality of interaction between participants as clients and health personnel at hospitals*

The results shown in Table 5.11 indicate some positive and negative encounters for participants at hospital. This research found that positive experiences included encouragement to join peer support groups, access to and provision of information on best adherence practices, feeling welcomed, and having an opportunity to report any other health problems; these findings are similar to the work of Stutterheim et al. (2017). The negative experiences were centred on lack of trust (as also shown by Dawson-Rose et al., 2016), long waiting times to be served, and poor confidentiality or lack of privacy, as well as being discriminated against, as also found by Stutterheim et al. (2014), including poorly trained health workers, as shown by Kennedy et al. (2017) and Stringer et al. (2016).

Inadequate management of side effects was associated with the general assumption that taking ART is always successful. Yet participants' frequent need for hospital appointments and contact with health personnel is an articulation of ongoing troubling aspects of ART, as shown by Young et al. (2019) and Squire (2013). Also, side effects were associated with sexual practices, which seemed to be due to a lack of treatment knowledge, similar to results by Thompson et al. (2015). Reports of sexual practices

showed that over 40% of participants were not enjoying sex or had no sex at all due to fear of infecting their partners – whilst epidemiological studies such as Maartens et al. (2014) and Simon et al. (2006) show that treatment can be a form of prevention, and more strongly, that successful treatment leads to more or less zero transmission risk, aspects of the epidemic that were not known by participants. This knowledge about treatment as prevention had not reached these participants. It appeared that HIV was associated with poor sexual life due to fear of transmitting the virus, even when participants were doing well on ART and were perhaps undetectable.

Additionally, the lack of timely responsiveness among healthcare providers was seen as a negative experience for teachers. Beyond being patients, these participants brought their professional status into their accounts, showing how they preferred to be welcomed and treated well on the basis that they were teachers. This study therefore differs from those of Livingston et al. (2012), Wolfe et al. (2010) and Whyte (2015), who researched civil servants and HIV in their work but did not clearly point to the use of professional labels in HIV care services. Participants in the current research foregrounded such labels, and considered using their profession to demand or seek better HIV healthcare service than other clients at the hospital.

#### *5.11.8 HIV and ART support from macrosocietal and meso-institutional sources*

The results on support structures illustrate that medication works best in the presence of social support. For example, families' as well as friends' support was described by 31 participants as important for accepting a positive diagnosis and adapting to ART, as other studies have found (McDonald et al., 2015; Skinta et al., 2015). Disclosure was common when it was about opening up to family and friends – who would help with ART – as Horter et al. (2017), Qiao et al. (2012) and Squire (2013, 2010) have also previously shown. Social support in terms of encouragement seemed important immediately post-diagnosis. Spousal support regardless of spouse's HIV status is a finding that has not been explored in the literature. Difficulties in finding a partner were reported as high among females rather than males, and associated by them with the problematic nature of being HIV positive and finding intimate companionship, as also shown by Squire (2003).

This research found that the media's role in HIV has changed compared with earlier in the pandemic, when HIV/AIDS was depicted as a crisis and as fatal, and content dissemination was mainly about prevention, as reflected in earlier studies such as Barnett and Blaikie (1992). Today, the media coverage of HIV issues seems to be different in that it has not only shifted from prevention to treatment but also has less content, projecting HIV/AIDS as a disappearing crisis in this ART era. Over 70% of the participants felt that the media did not fully promote ART-related health issues, especially online media. There is little recent work on views of media representations of HIV – especially not specifically HIV positive people's opinions – making this a revealing finding.

This research's results on support from family, friends, government, donors, NGOs and media differ from those of earlier studies, such as Siamwiza (1999), because support needs have changed from those around physical illness, health and recovery to helping with access and adherence to ART. For instance, NGOs are now helping with psychosocial needs through support groups, similar to findings by Lyimo (2013) and Nixon et al. (2017) in the global South. The finding here on material and sometimes social support from churches has not been much reported in other studies that address religion, such as Bond et al. (2016), Murthy (2016) and Pingel and Bauermeister (2018), as their focus has mainly been on condemnation and stigma issues at church.

This study shows strong participant views on HIV as conspiracy and povertisation – something that has been found all over the world (Doyal, 2016; Murray et al., 2013; Whyte, 2015). However, the contrasting finding in this research about the supportive elements of the biomedical citizen-state contract around HIV is fairly new, as treatment opens up a new way of thinking about this contract in the HIV context, and foregrounds a neglected national-political dimension of HIV positive people's lives.

#### *5.11.9 Foregrounding participants as HIV positive teachers*

What this study has found about HIV positive teachers specifically is that ART potentially leads to (de)professionalisation. It was clear among 60% of participants that the process of going to collect drugs, and some side effects, caused professional disruption and social embarrassment, as found by Bond (2010). For instance, dizziness and memory loss affected the teaching process for at least 24% of participants. Also, the

research found that 85% of participants were not comfortable with their status at school or their place of work, a finding similar to those of Flowers (2010:119) and Fylkesnes et al. (2013). Poor training in ART management skills was reported as a challenge and hindrance to developing HIV/AIDS-competent communities, as shown by Campbell et al. (2007). Having HIV positive learners and being teachers on ART made interactions hard, and was something not covered in training; teaching about HIV was also difficult. This research shows that care for learners by participants increased, but often then reduced when concerns about their own status eclipsed their resources to care for others. The study thus found that the need of teachers living with HIV to address their own status and health first is high.

Effects of ART on professional life are related to location, feeling fulfilled and 'normal' at work, and opportunities for career development, as shown in a study by Moyo and Smit (2017). The research found that problems with achievement-oriented assessments of teachers' work created extra pressure on their health condition; yet they also found comfort in the completions and achievement rates of their learners, which made their HIV positive status less pertinent and was even destigmatising for them. ART increased participants' ability to teach, a finding that differs from pre-ART studies such as Siamwiza (1999) and Kelly (1999), which showed an HIV-related teacher deficit through absence. Rather, this research found the use of professional agency to leverage better treatment and elevate participants in relation to people in general as well as health personnel who might condemn them for living with HIV.

This finding of a complex (de)professionalisation pattern of difficulties and gains arising from professional roles seems not to be covered in the literature, and could be a feature of the lives of other HIV positive professionals in high-prevalence contexts. This study therefore contributes a new picture of the complex representations of ART generated by people living with HIV and ART long term in the global South.

## **5.12 Chapter summary**

From the thematic accounts of results in this chapter, it can be contended that demographic factors, professional status, socio-economic factors, duration of being on ART, and gender may predict normalisation in the lives of people who are HIV positive and taking ART. This chapter has given a qualitative description and analysis of lives

lived with HIV and ART as described by participants. It has been shown that ART has both positive and negative implications for participants' relationships, resources, work and medical experiences of HIV.

The categories above amount to citizenship in several ways, starting with physical health and demographic factors, which make HIV experiences 'subjective' and affect individuals' work and interaction with others. Also, the long-term and short-term characteristics of living with ART are in part what create the biosocial norms that may be socially useful for HIV positive people's citizenship, especially when collectively dealing with complex ways of living with HIV. Ongoing medical uncertainty, and ART's transforming stigma without removing it, generate a commonly expressed and complex biosociality around these medicated bodies, which may form the implicit basis for participants' citizenship claims. The variable quality of interaction between participants as patients and health personnel at hospitals highlights the biopoliticisation of citizens with chronic health conditions and the management and self-management of their bodies. The different levels of HIV and ART support from macrosocietal and meso-institutional sources are connected to therapeutic citizenship techniques for managing bodies by individuals and strategies for controlling the population by the state. The findings that foreground participants as HIV positive teachers illustrate the personal, social and historical effects of the medicalisation and normalisation of HIV for a particular profession, which reveals the possibilities and limits in the everyday lives of teachers in Zambia as (de)professionalised professionals who are on ART. This aspect of the results supports but complexifies the conventional notion of citizenship, which signifies taking part in public life beyond the conventional political sphere.

These medical, psychosocial and material accounts given by HIV positive teachers thus provide an entry into understanding therapeutic citizenship. The chapter has shown not only the difficulties but also the successes of teachers living with HIV as a chronic illness from a psychosocial, medical and material resource perspective. However, there is an overlap across the results regarding medico-social issues that constitutes an evolving biopolitical phenomenon and a process of citizenship and 'citizenizing' that has developed and is continuing to develop within the HIV context.

In the next chapter, I address the higher-level themes that appear in the data as contributing to this HIV-citizenship process. To achieve this analysis, the micro themes described here are clustered into larger patterns, defined as middle-level themes of medicalisation, temporality and sociality, and are related to the theoretical problematics described in chapter three. The data is first described in terms of these middle-level themes and is then related to conceptual and empirical work from prior studies around such themes.

## **Chapter six**

### **Developing the conceptual framework into meso themes: from identity to sociality, governmentality to biomedicine, and chronicity to temporality**

#### **6.0 Introduction**

This study explores the process and nature of identity, governmentality and chronicity as mediated by the therapeutic citizenship status of HIV positive teachers in Zambia. This chapter gives a thematic map and is a discussion of the broader themes – drawn from the smaller themes discussed in the prior chapter, but related now to the thesis’s initial theoretical interests in governmentality, identity and chronicity – that emerged from the results: biomedicine, sociality and temporality. How these themes challenge and also take up the study’s initial conceptual framework is discussed. Again, throughout this chapter, participants are interchangeably referred to and foregrounded both simply as people living with HIV and also as teachers.

There are four sections to this chapter. The first section maps the larger, conceptually informed themes in relation to the data. The second section presents and describes these three key larger themes in relation to not only the data but also subthemes and literature. The third section focuses on how these higher-level themes confirm and contradict this study’s theoretical frame. The fourth section shows the connection between the conceptual frame coming out of this higher-level thematic analysis and existing literature, thus broadening the conceptual and empirical scope of the thesis.

Overall, participants’ representations show the multilayered and intersectional nature of HIV in relation to professional life, generational differences, and the social and economic aspects of life. These are related to the three meso themes developed, as they generally describe this chapter. This higher-level thematic analysis also provides some indications of how the study findings connect to therapeutic citizenship status, a relationship that will be examined further in the next chapter.

#### **6.1 Mapping (discursive) higher-level meso themes from results**

The process of analysing results in chapter five led to dominant themes. Also, a consideration of the initial micro themes in chapter five shows three broad meso themes: biomedicine, temporality and sociality. In Figure 6.1, codes that link with

specific features of the data are clustered into these larger meso themes, following Braun and Clarke’s (2013) approach. Coded findings show overlaps across results; for example, the self was portrayed in terms of medical narratives and the teaching profession.

The extent to which these three areas influenced participants in their capacity as teachers was interpersonal. Most of the meso themes represented in the figure below surfaced, and can explicitly be understood, in relation to the theoretical frameworks of biomedicine, sociality and temporality. For example, issues related to biomedicine were made prominent by themes of power, medicine and the body. The themes of biomedicine and sociality recurred throughout the data set. As Figure 6.1 shows, there is a significant connection between issues within each thematic category. The terms below arose from predominant categories discussed in chapter five that foreground findings and relate to the conceptual framework of this study.

Figure 6.1: Meso thematic (discursive) map

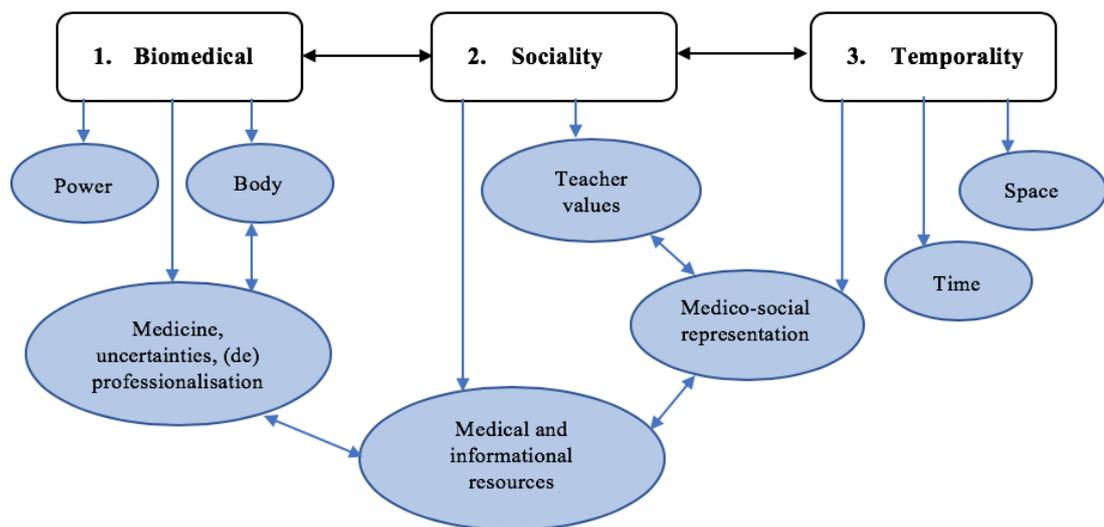


Figure 6.1 represents themes that depict the complexity of biomedicine, sociality and temporality as obtained from the results. Three discrete reasons can be argued for these identified themes. First, ART was seen as critical in how the body was managed, generating a concentration on conventional Western biomedicine that was strongly related to medication generally as well as other resources, which shaped ideas about the body, and that was articulated as a matter of power – of medicine, ‘patient’ and state. This relates to the theme of biomedicine. Second, representations of the self in social

context – the socialities of HIV – were shaped by medical and informational resource factors around living with HIV, as well as by being a teacher, and by representations of living with HIV and on ART within a social context. This explication relates to the theme of sociality. Third, the requirements of being on HIV have strong implications for temporality generally, rather than just chronicity. This temporality was also linked with articulations of space, medico-social representations and resources. The above three themes suggest reformed lives, reliance on prescriptions, the contiguity of mortality, and HIV biomedicine’s impact on social and professional norms. The sections below present and discuss these macro/meso themes as found in the data.

## **6.2 Thematic analysis of HIV biomedicine, sociality and temporality**

In the sections below, I am going to show how a higher-level thematic analysis, also informed by the research’s theoretical framework, leads to the middle-level themes listed above, considered one by one.

### *6.2.1 Meso theme one: biomedicine*

The various biomedical understandings have a wide range of applications across disciplines. As a theme here, biomedicine is associated with experiences of medicine, the body and power (Hughes, 2015:448). In this section, a presentation is given of participants’ representations of HIV biomedicine as a form of governing HIV, and how these representations extend conventional understandings of biomedicine. It is contended here that the usual understanding of biomedicine is too narrow. Elements of biomedicine explored here are drawn from participants’ general representations of health and illness in the period between diagnosis and treatment as well as over the short and long term of living with HIV and on ART.

#### *6.2.1.1 Living with HIV biomedicine*

Interviews with 38 participants showed the theme of biomedicine as driven by effects of ART on the body, professional life, the uncertainty of informational resources, and limited medical supplies for managing HIV. Most of the dialogue within the interviews was implicated within structures of medical institutions, and it was these medical forces that guided how participants’ social and professional lives were experienced. Taking the pill daily, and going for checks on viral load, CD4 counts and body weight, were all understood as biomedical practices, and also powerfully integrated with everyday

family, community and teaching habits. These biomedical ART practices suggested a sense of belonging to conventional structures of Western medicine. The association of HIV with biomedicine and biopower, and some of that association's social and temporal links, are illustrated by Njamba below:

Njamba (Male, 37): When I started the medication, I was told to take the pills because these days, people take the drug and live a normal life. They told me I could live a normal life as long as I adhere to the treatment. [...] I feel different because my life has changed. The life that I am living now is controlled. The control measures I'm talking about are me adhering to medication, a good diet, and to avoid certain things that can degenerate my health. I was not health-conscious but was reckless with my health. But now I am health-conscious. Because of taking medicine and my status. It makes me isolate myself. I feel am condemned person.

From the above quote, we can see that biomedicine, while it has its own characteristics as a theme in the data, is also powerfully linked to sociality and temporality. HIV's normalisation, mentioned by Njamba as achieved through ART, is associated with physical health, and not with self- or public beliefs about the fatal legacy and sexual behaviour of those living with HIV. Yet the nature of HIV biomedicine, even in this ART era, can be socially denormalising. Adherence practices make people who are living on ART pay attention to health issues more than before their HIV diagnosis, and also constrain them socially and temporally. Njamba's medically imposed social isolation was noted by him, and the medicine also gave him a 'condemned' status that perhaps limited his ideas of the future.

HIV biomedicine is multifaceted in this study, including traditional as well as Western medicine. Indigenous HIV treatment strategies were incorporated alongside Western forms of healthcare through ART by most participants. Although Western HIV treatment was followed, most participants embraced indigenous forms of body care. For example, Moola commented:

Moola (Male, 51): Well, there are things like products from Dynafarm that I do take once in a while: a special cleanser that detoxifies the body, and I

have taken crocodile fat, which is an immune booster. These products that I have mentioned do not replace ARVs. So I have not stopped taking ARVs to replace them with any traditional medicine.

Conventional medical information around HIV but outside of ART, however, was often not part of participants' representations of biomedicine. Lack of information on sexual life made some participants live unfulfilled intimate lives due to the fear of spreading the virus and being reinfected. This was at a time when the WHO (2015) had shown treatment was preventative for HIV. As mentioned by Nandi:

Nandi (Female, 54): My husband tells me that he is HIV free but I am positive. This thing has affected our sex life. I'm talking to you as someone I can confide in. I told him that because he is HIV negative and I am positive he has to use a condom when we have sex. That is so he can live longer when I am gone and take care of our children. I am a condemned person. I don't know where I contracted the virus from.

The assumed effect of ART on weight gain and changes in skin tone made the body a central measure of HIV treatment efficiency among HIV citizens. But this is not the measure of treatment efficacy that doctors use – another example of the expanded participant understanding of biomedicine. For example, ART's purported damage to the liver can be said to be based on uncertainty and lack of trust in ART. Consider Njamba's words:

Njamba (Male, 37): When I look at the way the virus attacks and the life expectancy of people who have the virus, I normally get a little bit scared. Because I cannot predict the virus and what it does to my body. I cannot also predict the effects of the drug that I am taking, especially on the liver. [...] Like I said, I cannot trust the medicine 100%. I doubt if the medicine can completely work for me.

It was clear that participants assimilated all sickness encounters to HIV – again reflecting the body’s vulnerability and the uncertainty of ART, even though many symptoms were described and could be considered ambiguous. The majority of participants lacked access to Western medical and informational resources, which made them vulnerable to a physiological uncertainty that denormalised their condition in and beyond the biomedical sphere. ART changes the body and appearance through such signs as skin rash and weight gain, and this physiological effect was central to many participants’ understandings of HIV biomedicine.

It can be reiterated here that what mattered in HIV biomedicine for participants was not always what was judged as important by biomedicine’s own most powerful makers and custodians. Also, the reminder of the pills was evident in repeated stories of abjection in many responses that were given by interviewees. For example, Nandi said the following:

Nandi (Female, 54): Because of the way I look, some people guess that I am sick. To tell you the truth, the medication has made my body weak. [...] Taking medicine is not an easy thing. If it was injectable, I think it would be better for me. If we could be injected for a year, like it is done for family planning, and then go for the other year. Taking pills every single day is not easy. Sometimes I forget, especially when I’m out of my home. I should take medicine at 18:00 hours. It’s already 18:00 hours, and I am still here at work. So, taking drugs every day is not easy, one needs to be disciplined. Wherever you go, you need to have the medicine in the bag. It is more like a demon we are worshipping.

From the above quote we can see that being in a profession can disrupt ART adherence, in the same way that HIV treatment can (de)professionalise life. The difficulty of taking medication at work and in open spaces relates to social vulnerability and the individualised governance of ART, which is also influenced by being told to hide when taking one’s pills, as indicated in Mwaka’s words:

Mwaka (Female, 43): I have friends at school who tell me that when I am with certain people, I should try to hide when taking the drugs. I tell them that it is part of me, and how many times am I going to hide? If I am in a group study in the same room, what would I do when it's time for my medication? Regardless of what people say, I'm free to take my medication.

The use of the phrase 'it is part of me' in the quote above demonstrates the strong connection felt by individuals between their ART medicine and their bodies. It also shows the medico-social identity that is constructed around HIV biomedicine and manifested through social interactions. HIV communities reported in the findings appear to operate on biomedical terms of being on ART that allow people to identify with each other, bringing about psychosocial benefits.

ART is a basis of a positive relationship between biomedicine and professionalisation. The majority of participants are able to work in spite of being HIV positive, just like anybody else, due to proper medication which when not adhered to can disable them from contributing and conducting their duties. It is the power of normalisation while at work, as seen in Mwaka's account, that adds to professionalisation:

Mbaeta (Female, 33): They [HIV drugs] are important because they are prolonging life. If I was not taking the drug, maybe this time I wouldn't be who I am. This time I am able to look after my family, and also I am able to work. I can do whatever others can do, and I am even better than they are. I am able to teach physical education and engage in the activities. I am very strong.

Participants' accounts of limited resources demonstrate views of state institutions' lack of capacity to deal with biomedical needs for a large HIV positive populace. Prioritising HIV over other chronic conditions by government and local or international organisations in Zambia exemplifies HIV biomedicine's wider and far-reaching effects. The provision and building of specialised HIV departments in hospitals is not only maximising choice in biosocialisation but also reinforcing a sense of difference between HIV positive and negative citizens. Thus, the majority of participants positioned

themselves as being part of a long-term national project through medical government support programmes, as commented by Sitondo:

Sitondo (Male, 42): Government on its own cannot manage us, because I have seen it with other drugs, when you go to the hospital you find that there are certain special drugs that are not there, but ARVs are in continuous supply. Because of donor aid, or maybe government has prioritised ART. [...] Government should not think of withdrawing aid at any time. Because the majority of people I meet at the hospital, some, maybe even me, if the subsidy was removed on drugs, we could not even meet it, and it means our death. Would like to urge the government to continue the good work they are doing concerning providing free drugs for HIV. If they discontinued this, most of the people would die, because they would not be able to afford to buy the medication.

Despite the positive self-positioning by participants in the citizen-state contract, HIV treatment has obverse uncertainties about the possibility that the state – or the international health state – will fail medically, especially through the ART supply chain's sustainability. As remarked by Kalaluka:

Kalaluka (Male, 49): The government supports me by providing the drug. The moment we hear that there is a short supply of drugs, I get affected. When I hear on television that there is a short supply of the drugs, I get sick psychologically. When I go for review and I am given for a month or two weeks, I get worried. Sometimes we hear rumours that the government will stop supplying the drugs, we get worried because we are surviving because of these drugs. When I stop taking Septrin I get affected, what more when I stop taking ARVs because they are no longer being given to us? That really gets me down.

There are several subthemes which emerge from the overall theme of biomedicine above. To start with, the findings suggest normalisation effects and illustrate the power

of ART medicine. This research found that power to work due to ART adds to normalisation, as individuals are able to take part in community affairs just like those who are HIV negative; this finding is supported by Lock and Nguyen (2018). The focus on effects of medicine on physical health by participants confirms a neglect of mental health issues in HIV care, which are present but ignored, unknown and untreated by the affected individuals. The power of ART is normalising, but only to the extent that it reduces infectivity and improves physical health, as shown by Flint (2015) and Kaufman et al. (2004). The power of normalisation adds not only to socialities but also to professionalisation.

The results on biomedicine indicate a level of sociality and the lack of it in HIV treatment. The biomedical strategies for managing chronic conditions such as HIV make social integration non-monolithic due to a network of medicalisation (Lock and Nguyen, 2018). This signifies a process of healthcare that positions and supports state as well as self-management practices of everyday medical needs (Strasser, 2014). Therefore, society as a whole is transformed due to the utilisation of biomedical technologies which extend effects beyond individual bodies (Lock and Nguyen, 2018).

There is a sense of closed time related to ART, which is a temporality issue. The time restriction of when to take medication is affected by place and surrounding people. This research found that ART has a strong time closure, which conflicts with being in a non-hostile space at the specific time of taking the medicine. The notion of safe spaces shows a sense of closed time that is psychologically created (Tucker, 2010) through social interactions and can be associated with mental health issues, such as anxiety when it is time to take medication in a hostile place such as a school.

These findings suggest that aspects of the body are changed by ART, and these changes are not recognised by Western biomedicine, even though they are socially reinforced. Medicine's effects on the body can be associated with the transformation, not reduction, of stigma. Additionally, HIV biomedicine cannot 'normalise' life on ART due to the culturally, socially and historically symbolic exceptionality of the disease, which is still seen as deadly but no longer as a fatal crisis – even though ART has changed HIV biomedicine into an extraordinary social condition, as also identified by Moyer and Hardon (2014). The role of medicine in normalisation is a physiological construct of

health and illness that neglects non-biological processes of functionality, as described by Won (2017).

This research found a lack of informational resources among participants on medicine and sexualities. There is a relationship between the body and ART. Although HIV care is about the individual, lack of informational resources renders the effects of ART collective by extending them to unsatisfied sexualities and a limited social as well as work life, as found by Endicott (2019) and Persson et al. (2017). Resources in biomedicine are uncertain due to manifestations that need to be acted upon every day in health and illness management, as shown by Lock et al. (2000).

The uncertainties reported within the biomedicine theme were mainly due to lack of medical resources, ART side effects and fluctuating health conditions. The findings confirm that living with a chronic health condition offers no certainty on resource requirements at any given moment, and has unprecedented medical side effects on the body, as also found by Cooper et al. (2013). This is because strategies adopted through medical treatments and health against potential risk outcomes can be driven by socio-political factors (Foucault, 2008; Novas and Rose, 2000). These results reflect those of Flowers (2010) and Squire (2013), who also found that medical normalisation in HIV and ART is connoted in terms of physical health, not state or social relations.

The findings here provide evidence that teachers who are HIV positive experience some level of (de)professionalisation through ART biomedicine. Literature reviews have indicated that there are no studies that explore and examine this finding about ART (de)professionalisation. Similarly, no research highlights the descriptions of medicine based on opinions of those who are living on ART. On one hand, the demands of living on ART can be (de)professionalising to some extent, as side effects and hospital appointments disrupt the work of participants. On the other hand, and as seen in chapter five, ART is enabling: participants were able to do their job due to the power of the HIV treatment, which was primarily reported to be effective in improving physical health and abilities.

Nonetheless, the medicine was described as a 'demon' by some participants, if only to signify the difficulty and time-restricting nature of ART's demands. The representations

of ART as an integral part of everyday living are problematic not only for the body, but also for the medicine demands that limit social, economic and profession life, as also found by other studies (Persson et al., 2017; Won, 2017; Lock and Nguyen, 2018). The findings suggest that medicine is restricting, socially and professionally: hiding or not hiding, and hence socialisation when on ART, appears contrived and hard. The findings indicate that chronic health conditions managed by daily medicine, such as ART, have positive and negative effects on individuals' and groups' social and professional lives – a feature of 'biological citizenship', as shown by Rose and Novas (2005).

This research found that participants' power was determined by state help or lack of it, as well as by uncertain international help, especially around medication resources. These results are in agreement with those obtained by Endicott (2019), which show that the HIV pandemic is about power or its absence within a state. Also, resource availability is part of power against the framing of the uncertainty of help from national and international agencies. Participants' interactions among themselves, with others and with health personnel, as well as their relationship with the state, lead into the discussion of sociality in the next section.

### *6.2.2 Meso theme two: sociality*

Sociality as a concept holds that differences among people are not only about class, race, gender and place, but also other factors, such as professional status and health condition, determine the degree to which individuals associate with groups and social cooperative formations (Harfitt, 2014:8). The interconnection between the socio-political and the pursuit of personal well-being can be attained through socialities from a health and illness point of view.

#### *6.2.2.1 HIV sociality: the otherness of living on ART*

In the data from this study, there is a connection between participants' representations of their health condition and their framing of their social relations. The process of transitioning into ART is associated with various forms of representation, but representations of social HIV outcomes differ based on gender. Eleven men in the sample said they had found it hard to socialise after HIV diagnosis, while women had easily extended social clusters with fellow females, especially those who were also on

ART, as also found by Whyte (2014). Therefore, emphasis on gender as the basis for social group formation and inclusion is high among women participants.

Decisions to collect HIV drugs from a more distant district hospital show the social relations of HIV stigma operating, even in this treatment era (Bonnington et al., 2017). Not wanting to be known to be on ART by neighbours forced some participants to seek treatment in faraway hospitals where they were not resident and not known, as shown in Mweetwa's remark:

Mweetwa (Male, 42): Let's just go there and not here, because most of these people are our friends here, so we decided to go into Mongu District. [...] Because I know the kind of community I live in. The people in my community were going to stigmatise me.

For the majority of participants, identifying some individuals as supportive, and telling them about their diagnosis, helped with adhering to ART and promoting good health practices. Continuous active involvement in social networks of family and friends was key in enabling some participants to test, start treatment and manage a life that was reliant on ART – including through group programmes and peer support. The use of the term 'member' of an HIV sociality is more appropriate than 'client' of an HIV service (Whyte, 2014), because 'membership' as opposed to 'clientship' helpfully highlights not only service dependence or utilisation but also important personal relations. The normalising effect of recognising oneself as a member of that sociality was depicted by Choolwe:

Choolwe (Male, 38): When I was not on medication I regarded people on ART as not being normal. But now that I have the knowledge and in the same situation, I think differently. So, I would say that scenario is just in me.

In the statement above, a sense of normalcy when diagnosed with HIV is situated as a social interaction issue. The normalcy of 'staying healthy' with HIV, and the awareness of having a virus, have some underlying intensely social and/or asocial features.

Consider Mweetwa's representation of illness as driven by societal factors in the requoted extract below:

Mweetwa (Male, 42): I feel the mind is supposed to function normally, but according to what society has perceived as to what this what is normal, if I go contrary to that, they [members of society] will say I am ill. So, in simpler terms, illness is doing things that are against what society perceives to be normal.

Two things can be noted in the above statement. First, it is necessary to have a *mind* (not just a body) that conforms to what society prescribes as normal in order to be considered 'healthy' and not 'ill'. Second, illness is defined by the collective actions of society that specify 'normal', and any deviation from that is deemed as 'illness'. Also, Mweetwa's remark suggests that being 'normal' through ART is not only a biomedical issue, but also psychological and social.

It is interesting that participants described their actions and experiences of living with HIV and on ART so extensively in terms of other people. Although individuals made decisions and had the freedom of self-care, other people's reactions regarding their condition mattered. As Lilato said:

Lilato (Female, 42): In life I have discovered that people in my situation suffer, for example when I discovered I was positive, my hubby asked me how I acquired the virus. Instead of encouraging me and helping me so that we can move on, he was ever pushing me, and I started thinking of ending my life so that people will not ask me questions.

HIV redefines psychosocial configurations in interpersonal relations and communities. For six participants, not having any family support had some negative effects on physical health. Similarly, lack of family support can be associated with participants' own difficulties in acceptance, as found by Bond et al. (2016). The study data on support systems suggests that, apart from family and friends, the treatment programmes themselves also provided unique forms of sociality for participants:

Maata (Female, 46): We went through the home-based care. They used to give us soya beans, cooking oil and other types of foods. The home-based care used to buy us drugs.

The use of 'we' by Maata refers to HIV socialities and group solidarity, which demonstrates that cooperative societies existed even before free ART access programmes. Contrarily, Mutukwa's words below clearly highlight the social complexity of interacting with others when one is on ART and living with HIV, from the local to the national and transnational.

Mutukwa (Male, 39): Once people know that I am on ART, it becomes a problem. Let me give you an example. I might be in a group and pass a comment about a beautiful woman. If people know my status, they might remind me and say, 'you are HIV positive and so you are not supposed to think of sleeping with her'. If I ask such a person who told them that I was on treatment, they might say, 'I am just joking'. That would embarrass me, and I would know that people are talking about me. I think Zambia is not like other countries, actually the whole of Africa is still a problem when it comes to disclosure. If I disclosed my status to someone, they would tell other people about me, and I would be stigmatised. They would not even want to share cups with me. [...] I am not imagining [these things] are happening. I hear people telling each other that they should not give someone a cup because they are HIV positive. I have seen people being stigmatised. [...] If I disclosed my status to someone, they would tell other people about me, and I would be stigmatised. They would not even want to share a cup with me.

Based on the extract above, it can be argued that HIV disclosure is not a one-time event, but a process affected by medical factors and social relations. It seems time and physical place too can enhance feelings of stigma and experiences of discrimination. Self-reconstruction and non-disclosure in order to conform in various spaces were necessary

for the majority of participants. For example, teachers project themselves as role models in society, yet being HIV positive is associated with stigma and self-stigma, breaking communal or social moral norms, and generating guilt about behaviourally acquired HIV, as noted by Sumbwa:

Sumbwa (Male, 39): Sometimes I am bothered. Because when I go to get medication sometimes, I don't feel welcome at the health centre. Sometimes when I go to the health centre, I get exposed to a lot of people, and some of the health practitioners do not understand me as a civil servant. This is because some of these people that give us medicine are just caregivers from the community. Sometimes they do not handle us very well. I get delayed by the volunteers because they do not understand that I need to get to work.

Encounters with HIV's otherness start at the hospital, as noted in the quote above. Being seen in open queues of those receiving ART drugs at the hospital, and needing time to get back to teach, adds to both the sociality and (de)professionalisation narratives about living on ART. Additionally, being served by volunteers during hospital appointments was pejoratively described here (and by other participants), as most of these community health workers do not have full medical or nursing training. Sumbwa presented them as non-professionals who were judging the lives of professionals, whom HIV had led them to deprofessionalise.

Both the continuous nature of treatment programmes and the need for social support generate distinct forms of sociality. For example, we notice in the findings that at the start of ART, several participants who had adapted fast to the treatment had had people who helped them through the transition to taking their medicine on a daily basis. Mudenda put family support first, despite prioritising religion:

Mudenda (Female, 39): I have selected some members of the family who have to talk with me over the same problem. If I happen to complain, they come and start interacting with me. But mostly I do get my bible and read. And telling my conscious that cannot reverse this situation, but I just have to move forward.

The quote above shows that seeking helpers through peer support groups from clinics by service users is about having family. The need for acceptance from others was high, especially in the early stages of diagnosis when they were coming to terms with their status. In this regard, these results further support the idea that presentation of the self in HIV is more relational than personal, as also found by Bond (2010) and Whyte (2014:17).

The act of concealing and revealing the ‘HIV self’ is an aspect of power manifested in sociality. To gain control over their health condition, participants demonstrated that they needed to monitor themselves in all groups and situations. When participants spoke of concealing their HIV image, they displayed a consciousness of not being able to freely take medication without any disruption. However, uncertainty over how to manage a long-term medical condition also led to building relations that were useful, even in workplaces. Consider Sitondo’s remark:

Sitondo (Male, 42): My DEBS told me to say these ARVs are just like food, so it is from that angle actually that I take ARVs as food. He used to tell me that food, you see, we take it on a daily basis, so there is no way one can feel stigmatised by self or others for taking food. So, it is that in that sense that I take ARVs as food. Even when I used to go for collection of medicine, I used to hide, but this time I just go openly. [...] Because it is psychological. [...] If I don’t disclose and people start knowing about it, I will would feel bad if I hear people talking about it. So, when people talk about it when I have told them, then it does not become an issue. So, it reduces its power on me. Actually, disclosure is a strategy, unless maybe you have a hidden agenda, that if I disclose women are going to run away, but I am already married, so I am not worried of that.

The above remark shows daily acts grounded in ART and directed towards HIV’s socialities – here, involving a workplace superior providing supportive advice – exercised in a workplace environment.

In order to avoid some external barriers to outwardly embracing an HIV image, co-construction of the self within social collective experiences is inevitable, as shown by Flowers (2010). It is during the reimagining process of self-identity that patients are able to normalise and socialise. The process of constructing a shared HIV image is situational, as illustrated by Sitondo above. HIV positive teachers experience ART through solidarities and alliances. Ngolwa describes the importance of having some interaction with others, despite privacy about being HIV positive:

Ngolwa (Male, 52) It is heart-warming to have someone to talk about this to, someone, it is not every day that I do this. I cannot talk to everyone [about HIV status] but have to choose whom to talk to.

Even though it is often done cautiously, the identification of individuals to talk to about an HIV positive condition is empowering. HIV solidarity among participants is about individual premonitions of disclosure. Hence, at the centre of HIV solidarity in the context of sociality is trust, acceptance, and being aware that taking ART is not to be differentiated as a problem of others, as found by Bell et al. (2016).

Identifying others who are also living on ART initiates the process of socialising for individuals and in groups. HIV socialities are strengthened by location and gender demographic factors. Reflecting on the self as being different and/or similar to other citizens begins with an awareness of being HIV positive and knowing members in the locality who are on ART, especially through the hospital. Therefore, at the centre of the formation of social groups and the development of kinship ties based on HIV is location, which provides physical spaces for interaction around the diagnosis. The gender dimension of sociality is seen in women's cooperative responses to individuals in a school. Although female participants associated in groups for recognition, males interacted cooperatively due to biosociality, albeit mainly in secret, as shown by Rabinow (1996).

Social class has a direct effect on how HIV socialities manifest themselves, as participants formed a sense of self-identity around their diagnosis through their status, economically and socially. There is an association between participants' middle-class

status and aspects of social actions that relate to behavioural changes and good health practices. This class-related finding, and its connection to health, is similar to results found by Marmot (2015). HIV medicalisation affects the immediate social relations of people living on ART and others. This finding on HIV teachers' solidarities has not been explicitly covered in existing research.

The demands of ART and social reclusiveness are connected. HIV disclosure is to a large extent a source of group formation through mutual recognition by those who are also HIV positive. Additionally, sociality aspects in HIV reveal that the institutional setting and social relations of living on ART play a critical role in the disparity of outcomes in relationships, professional networks and competencies, as shown by Whyte (2015).

HIV communities can be established and sustained by an overarching political structure that creates a sense of nationhood. Findings on the sociality of support suggest that ART has some organising effect, through self-help strategies and larger group strategies; for example, those who are HIV positive may systematise themselves as being one people. This finding that – they are 'one' in the opinions of participants – differs from other studies (Lock and Nguyen, 2018; Camlin, 2017) that found a more individualised than collective sense of HIV socialities and care.

Sociality is a continuous and not a fixed process in HIV, due to ART demands as well as fluctuating health statuses. The results of this study show that social life is changed after an HIV diagnosis and throughout treatment for most participants. These changes involve reduced peer interaction, reordering of social activities due to being confined, reductions in the size of friend networks, and intensification of close relationships with others who are also on ART. The physical health of participants was a basis for social life changes and the reorganisation of networks of peer groups and allies to include medical aspects, as also found by Whyte (2014).

From the above, it can be contended that HIV socialities remain socially situational, institutionally absent and medically subject. Most of the HIV otherness factors identified in this section are related to participants' ART experiences in the past, present and future. When living with HIV, people carry the past with them, and become

concerned about themselves in the present and also their future selves. Biological differences related to an HIV diagnosis are essential in the social connections of therapeutic citizenship in the long term. Biologically based socialisation develops over a period of biomedical intervention – which brings in the theme of temporality as it relates to living with HIV and on ART in the section that follows.

### *6.2.3 Meso theme three: temporality*

The period between diagnosis, treatment and recovery is a temporality issue in HIV. In this study, participants recalled incidents of illness attacks on the body by comparing their past health condition with the present state of their physical health. Thus, past experiences in chronic health conditions, especially of body pain, become an amalgamation of the present in the future (Morton, 2007). The effect of the drugs, as a parallel to recovery (in phrases such as ‘back then the body was weak’), has clear overtones of the idea that the present matters more when it comes to chronic illness than the past. This research found that experiences of being on ART create medical histories that are not linear. This implies that HIV treatment has different effects, and thus coping mechanisms vary across gender, age and period of being on ART.

#### *6.2.3.1 HIV temporality: the everydayness of ART*

Chronic health conditions present the body as material for managing the present and mapping the future. For most participants, the frequency of taking pills acted as a reminder about having ‘something’ wrong in the body that required medication every day. This internalised awareness of the long-term taking of pills resulted for some participants in defaulting on their treatment. ART adherence is an HIV temporality issue due to medical as well as non-medical orders of events that relate to living with the virus. For instance, experiences of HIV-related bureaucracy – such as monitoring medical records or accounting for pills – and a lack of improvement to physical health while on medication all point to questions of temporality.

Participants who were sick at the point of commencing ART reported some physical health problems that continued while they were taking medication. Being and feeling different depended on the period of HIV treatment for many participants. The negative emotional and physical experiences reported by some participants reflected the process of adapting to new bodily and psychological conditionings of life on ART. Thus, with

temporality, the debate as to whether HIV positive people are ill or healthy is covered by what Boorse (1977:554) calls ‘functional ability’. Take for instance Mukela’s remark below, which shows a conflict between physical health improvements related to ART and the challenges related to when exactly medication is to be taken:

Mukela (Male, 31): It’s been okay, but no one wants to be taking drugs on a regular basis. You always have to remember to keep time, so it is a challenge on that aspect; obviously the bitterness, the frequency, and the idea of not having to let them go at a point in time. It is challenging.

The long-term nature of HIV medicalisation, in this extract from Mukela, is posited as a challenge and worrying. In spite of the negative aspect of unending ART practices, the temporality of HIV enables ART adherence techniques to be learned and treatment requirements assimilated in the long term, a finding similar to the work of Benton et al. (2017). By going back into the past – for example, the time of diagnosis – participants interpreted and invoked a form of temporality that shaped their own present reality and forging of a future social identity. As Choolwe commented:

Choolwe (Male, 39): Before I knew my status, my health was retarding, but after I was introduced to ART I picked up and came back to normal. I was down and would feel weak. When I look at the photos I took that time, I do not like how I looked.

The extract above illustrate that counter-narratives emerge on the basis of the period between HIV diagnosis and treatment which shift or confirm behaviour to align with an ‘HIV self’. How people experience an altered lifestyle depends not only on beliefs and perceptions but also on the physical impact of the need to become accustomed to living on ART and with HIV.

Lack of cure and alternatives to effective HIV treatment drugs appeared to constitute the recurring pattern of the self as process of becoming for the majority of the participants. The unforeseen vulnerabilities of managing illness could be associated with retaining an identity that was built on experiences of living with compromised

immunity. Thus, self-identity was appropriated by physical recovery, not towards acceptance, but often towards resignation and loss of self. This is reflected by Sitondo:

Sitondo (Male, 42): I used to feel I was no longer myself, but eventually that came to an end after two years. Then I started fitting in so well. When I had that self-stigma, I even used to withdraw from others. Withdraw from work, being lonely.

The account of Sitondo above offers a form of implied meaning through such phrases as ‘then I started fitting in so well’. This social element of HIV positions the self in a positive way, despite the complexities that are sometimes limiting when medication is incorporated into daily routines. Although self-care in HIV is important, the social imposition of individual responsibility reflects a long-term intensification of social relations.

The factor of time is central in chronic illness, as present body experiences influence imagined future medicalisation. Both past and present are contingent subjectivities that structure the finite everydayness of life on ART (McDonald et al., 2016). Therefore, temporality makes possible the unity of existence, which constitutes the structure of care framed in a collective manner. HIV temporality extends the understanding of health in a holistic and integrative sense of an imagined and (de)attached physical self. The temporality of a chronic health condition makes assimilation of medical requirements possible (Pallesen, 2014). However, self-determination through ART is challenging in the absence of a cure. As Mutukwa remarked:

Mutukwa (Male, 39): The only thing I find challenging is the fact that I have to take my drugs for the rest of my life. And the fact that there is no cure for HIV. [...] It was difficult for me to accept. I could not imagine myself or to the hospital for treatment and take medicine every day.

Being an HIV citizen involves the process of learning and relearning over time to integrate medicine into one’s life. This is what might be called the routinisation of ART practices: going to collect medicines from time to time; remembering to take medicine

every day and at a specific time. However, it was not the participants who incorporated their medicine into the everyday, but rather ART led to life adjustments over time by which adherence and self-acceptance were guaranteed, as seen in Lutangu's articulation:

Lutangu (Female, 40): The medicine has become part of me, and I don't really feel that I am bound or anything like that. It's not a burden to me but something better, that's the way I look at it. It's not a burden to me.

The extent to which someone will see ART as a burden depends on temporality, i.e. what stage of the process they are at, with the eventual culmination of knowledge about HIV management (Hill, 2018). Thus, the everyday intake of ART is a long-term action based on the fear of what bodies can inherently become over a life course in the absence of HIV treatment. It is interesting in the findings to note that being on ART was seen as the only way of avoiding early death, with clear temporal overtones, and also eliminated others' suspicion that one was HIV positive, based on an improved physical appearance, for example. This can be seen in the extract below from Sitwala:

Sitwala (Female, 53): I am just the same because nothing has changed apart from taking the medicine, but no one can tell that I am a patient.

From the above quote, we can see that ART makes HIV invisible through improved physical health and bodily appearance. It was this invisibility that improved social relations for people living with HIV. Therefore, the reported reluctance to disclose could be associated with non-visible HIV symptoms, even though being on ART was what caused the difference. HIV sociality is paralleled by the everydayness of taking ART.

The findings above on the overall theme of temporality can be understood in many ways. First, ART experiences change and become complex with ageing. The results show that the period on ART influenced participants' bodily changes. As participants' ages increased, their HIV treatment needs became complex, with claims by about five participants that ART was making them age faster – a view that has not been explored

in HIV research. The complex treatment needs of HIV are associated with both age and gender differences, because men face more biomedical complications while ageing on ART than females, as shown by Thompson et al. (2015).

The gendered difference between year of diagnosis and commencement of treatment is high and reversed between men and women, as also observed by Amin (2015) and Fleming et al. (2016). Elderly female participants who had lived with HIV for a long period appeared to value and maintain social relations. There were more males than females who had either tested late for HIV when sick or had commenced treatment after a long period of denial and self-stigma.

Generational differences are eminent in illness and health due to medical and social changes. Living with HIV is about categories of individuals based on generations. This research found that ART experiences are on a spectrum aligned with age group and treatment commencement period. For example, participants who had started ART in the early 2000s demonstrated gratitude, adaptation and less difficulty, while those who had started treatment for HIV in 2010 and were much younger by age reported overwhelming effects of ART. These ART generational differences in relation to citizenship have not been previously studied by researchers, and nor is this covered in the HIV literature.

Assimilating ART demands involves a long-term process of inclusiveness and knowledge-gathering on HIV care. Successful adaptation to ART is essential for both social and medical normalcy in chronic illnesses that require daily medication. Although it is often described in terms of past, present and future, this research found that explicit discussions of HIV treatment and care are more focused on the future than the past. Strategies for adjusting to ART are not homogeneous but differently shaped by small- and large-scale management techniques, social phenomena and time. Therefore, adapting to ART involves a long process of physical health recovery, which makes the time factor crucial in chronicity, as also found by Karimi (2010). Participants' reflections on historical encounters with HIV and ART seemed to be based on uninvited medical impacts on self-care and care by others in the long term.

The purpose to adhere to ART is an integral part of self-imagining that is often related to past hardships and future uncertainties. Participants' ART experiences and HIV chronicity were described with great importance, related to improved physical health and a medical process that was always changing and uncertain. The importance about learning of HIV care attributes in results can be associated with temporality of knowledge acquisition and skills development in a given period, as also noted by Harfitt (2017).

ART continuity offers a sense of closure with an HIV diagnosis after at least a year due to self-stigma and denial. But this sense of coming to terms with HIV for participants was shaped by place and the forms of interaction at any given moment, due to the non-linear forms of HIV temporality. Also, an emphasis on self-management and social relations across time and space in the findings points to resource constraints, anticipated and real stigma, and institutional (such as school) and racial discrimination, similarly to Hill's (2018) findings.

The theme of temporality in HIV is rooted in the frequency of taking ART, which was described as hard and inconveniencing for many participants. This research found that the taking of HIV pills was disruptive, distressing and tedious, mainly because of the requirements and restrictions of medicating the body, even when one is feeling fine, at the same time every day. Despite the difficulties of timing and synchronising ART with other life routines, minimising the potential risks of non-adherence to ART (i.e. developing a drug-resistant virus, headaches, changing regimens) is a motivating factor to remain on HIV drugs. Hence, the theme of temporality is developed further to demonstrate the (dis)order of things, events (medical and non-medical) and understandings of time as affected by living with a chronic condition. The individual representations and everyday hardships of ART found by this research have not been extensively covered in HIV research.

Having discussed the three meso themes as they emanate from the results, the next section of this chapter addresses how some findings, extrapolated through themes, fully or at least partially support the conceptual framework.

### **6.3 Consideration of findings and themes in relation to conceptual framework**

Here attention is given to findings that fully or partially support this study's conceptual framework and its relation to the emergent themes. Descriptions of illness and health produced responses that were associated with the concepts of identity, chronicity and governmentality. For example, the reported use of specific local herbs and natural wild fruits while on ART to supplement the diet is a reflection of HIV governmentality and self-care. This shows us that HIV care goes beyond Western medicine to include indigenous means of managing HIV chronicity; it also shows that ART and indigenous methods of illness treatment can work side by side. Also, the long-term and short-term effects of ART are a foundation for establishing an HIV identity that can be experienced individually or collectively (Lock and Nguyen, 2018). In this regard, the sections that follow show the association of identity with sociality, governmentality with biomedicine, and chronicity with temporality.

### *6.3.1 Identity and HIV sociality*

In chapter three, and on identity, it has been noted that changes in behavioural patterns are associated with ART practices that have been socialised. Social identity changes take place within individual and collective social dimensions of interaction as mediated by medical factors in a given space and time (Tucker and Gooding, 2018). Similarly, findings on self-descriptions suggest that medicating bodies is the basis of an HIV identity, self-concept and esteem, created mainly through clinical diagnostic categories of either physical or mental health issues, as shown by Tucker (2009, 2010). Both negative and positive experiences at hospital reinforce an HIV identity. Self-identity in HIV is driven by medical factors played out through social relations. For example, daily ART management, state control of pandemic policies, and long-term provision of healthcare services make HIV chronic living intersect with community, as shown by Wahlberg and Rose (2015). Findings such as fear of death and health uncertainty form part of HIV socialities that reveal ART as having an identity effect on collective living with a chronic health condition. Consider Nalu's comment:

Nalu (Female, 31): I felt I wasn't alone. Because at first, I used to feel guilt to say maybe am alone. But when she opened, I realised I am not alone. We are many who are supposed to fight the battle.

This remark by Nalu reflects a biomedically driven story of identity. Although differently described, the social, political and physical ‘health’ of participants shared the same basis in living with HIV. Participants generally agreed that their free ART was a right, which also affirmed a framing of social identity driven by HIV. Although HIV identities appear medically fixed, they shift based on social and health fluctuations. For example, the subjectivities involved in revealing a biosocial image informed by ART could possibly interfere with the way participants carried out their work, as reflected in Mbaeta’s remark:

Mbaeta (Female, 33): I do not trust some people. I think it will affect my work, because there are certain people who would tease me or something like that, and I would lose concentration at work. The problem is, we don’t disclose to anyone. But there are two teachers who are also on ART who are very friendly, and we talk and chat.

The quote above reflects the difficulty of group solidarities due to anticipated stigma, and the possibility of socialising based on being on ART. Subjectivities involved in ART experiences can lead to testimonies of a shared identity narrative through medicalisation for possible support and integration. Thus, self-imaging for several participants was predicated on the psychological and social effects of being on ART, which mainly attracted shame and isolation, similarly to findings of Ho and Goh (2017). Also, being ‘normal’ is questionable for some participants due to their daily therapy to suppress HIV and comparing the state of their bodies before the start of their ART, and also in terms of life without HIV. There is tension in syncing social and medical identities. From the findings, it can be maintained that those who succeed in maintaining relationships after an HIV diagnosis have to some extent disclosed and freely incorporated their HIV status in their social networks.

HIV sociality provides an initial step to identity normalisation through disclosure. To receive support, a certain form of social identity needs to be established, recognised, and not integrated into mainstream cultural identity, which goes beyond family and friends to include the workplace and the whole community. Fear of being labelled ‘different’ and wanting to fit into the social fabric prohibits disclosure and predisposes some participants to self-exclusion, as mentioned by Sililo:

Sililo (Male, 35): I have not disclosed my status at work, so I am able to mix freely with everyone. [...] It's because of these issues of discrimination. [...] I can feel isolated from others, and it might affect my performance in my general way of living. Because there are certain things which I go through that others do not go through. Like taking drugs and managing how to live in a different way.

From the quote above, being HIV positive and on ART can be associated with an internalised form of sociality that can be revealed for group inclusion and even exclusion. It was this uncertainty that caused some participants to craft double identities: an HIV image embraced in private, and a professional public-facing image. However, the distinctiveness of populations such as those with HIV can be a basis for recognition through difference from the rest of a given nation.

In this regard, the notion of nationhood finds interpretation in HIV sociality through support structures and the sense of belonging created by HIV citizenship. For example, reference to collective ownership of HIV through language, by use of words such as 'we' or 'us' in several interviews, resonates with how identity can be constructed around illness and used as a form of social world that represents a specific group. The need and usefulness of identifying someone for support by participants in their medicalisation process is fundamental for HIV sociality. The multiplicity of HIV biomedicine is driven by macro, micro and meso levels of ART governmentality, which is the focus of the next section.

### *6.3.2 Governmentality and ART biomedicine*

The findings on HIV illustrate the macrosocietal and meso-institutional frameworks of how HIV is governed. For example, government policy on mandatory HIV testing for everyone who visits a hospital with an illness, as well as the formation of HIV teacher associations in Zambia, are both forms of governmentality. Similarly, personal initiatives to teach others about HIV signify a testimony aimed at creating positive public attitudes about ART and being HIV positive. Take for instance Maata, who openly spoke about her status at work, which depicts a meso level of HIV governmentality:

Maata (Female, 46): I even hold meetings with my teacher colleagues and tell them my condition. It has helped me because people do not point fingers at me, because they know that's how I am.

The quote above demonstrates a form of HIV biomedicine that is integrated into a person's professional and social life. The governmentality illustrated in Maata's remark is more psychosocial than biomedical. However, the results show that participants failed to successfully and interactively merge their medical life with other aspects of their social and work life.

At a micro level, participants outlined their long-term and short-term experiences of HIV and their different experiences of ART. The psychosocial and physiological impact of ART governance relies on the curative nature of HIV medicine. This study has shown that participants were controlled by clinical encounters, which extended the biomedical effects and effects on social and mental well-being in their communities and at work. Through the findings on short-term experiences of ART, the concept of governmentality helps us to understand that these HIV positive teachers saw their health condition in physiological terms, and thus the manner in which they managed themselves was centred on the body and not the mental side effects of ART.

Managing physical, mental and social life while on ART is best viewed through the lens of governmentality. Exercising, following a balanced diet, keeping oneself busy and socialising with others are forms of conduct on self-care or self-regulation. Similarly, findings on behavioural changes due to HIV relate to a 'conduct of conduct' (see chapter three) that allows groups to be distinguished as peculiar through ART medicalisation culture, as also shown by Bulley (2014) and Nye (2003).

HIV governmentality is to some extent based on gender differences, particularly around spousal disclosure. Several women among the participants spoke of not disclosing to their spouses for fear of divorce, while others mentioned that their husbands had to permit them to go public with their status, if they had to do so. It appears that the majority of women felt obliged to tell their partners about their HIV diagnosis, but it did not seem to be the same situation with men telling their female partners. Let us take for

example the story of Mwangala, whose husband died without ever disclosing his status, only for it to be revealed after his death through hospital records:

Mwangala (Female, 49): When my husband died, I was living positive but was not yet on ART. My husband was not talking to me, so I did not know whether he was positive or negative, or if he was on ART or not. When I asked him to take me to the hospital so that I can start treatment, he would refuse and told me to go on my own. He would say it was I who was sick and not him. I didn't know his status, he was hiding until he got sick one day and died within a short time. He died of the same. I discovered that he had a file at the hospital and was on ART. I got very disappointed. [...] I never saw any medicine in this house, nothing at all. Wherever he was taking it from I do not know, but he had the file at the hospital. His family questioned me, and they thought I knew what was happening with him and said I was the cause of his death. I tried to explain but to no avail. They got everything we owned and left me with nothing but my two children. It took time for me to cope. From that time, things have never been bad.

The above extract depicts the deep gendered management of HIV, especially around spousal and family disclosure. There is a secretive manner in which couples govern their own HIV, which in many ways hinders full treatment adherence. While the above story confirms that most males are unwilling to disclose their status, it also substantiates societal and indigenous norms around women being seen as responsible for any crisis around health and illness practices – such as infertility, but of more relevance here in relation to HIV infection.

ART is entrenched in events that describe the body. The identification of ART's workings on the body signifies control and indirectly fosters a restricted social life that secures membership of a medically defined community. Although useful in sharing information on self-care (see also Campbell et al., 2012), support groups are a source of demotivation and misinformation about the long-term effects of ART on the body. By

sharing negative experiences and even death, fear and uncertainty about being on ART arise in these communities.

Macro manifestations of HIV medical governance include the relationship between the state and participants. The institutionalisation of HIV treatment supplies and the prioritisation of ART supply position the state as a custodian of population control. For example, findings show that while participants' health had moved to the domain of self-management, there was still state provision, especially through medical resources. The politicisation of HIV was noticed in responses about different levels of governance. The state-participant connection is a national issue of HIV governmentality, which is driven primarily by the state's role in treatment and care services, as also stated by Squire (2016). I move on now to consider views about HIV internationalism and power within and against the state.

In referring to Africa and donors from abroad, as noted in the results on support, participants were aware of HIV as a global project of governmentality. Therefore, claims and rights were stated by participants to both the nation-state and international agencies. For example, HIV governance through global policy frameworks and interventions, such as the 90-90-90 goals, is a clear indication of the national governance of HIV as adopted from international action plans. However, the need for locally made medical interventions, as seen in the findings, can be associated with the absence of information about the workings of ART and the benefits of external interventions. The fact that the government cannot reach disadvantaged groups with HIV, especially in rural Zambia, has resulted in fewer or no biomedical tools for tackling and managing HIV chronicity burdens (De-Graft et al., 2010). In the next section, chronicity is explored in relation to the findings on theme of HIV temporality.

### *6.3.3 Chronicity and HIV temporality*

The incurable but treatable nature of HIV makes it a chronic health condition. In the findings, the majority of participants described themselves as ill because of the chronic nature of having to take medication daily and long term. The effects of ART temporality associate systemic poverty, interpersonal relationships and a subjective sense of closed time with HIV's chronicity. Accordingly, chronicity constitutes both biological

citizenship and social elements through which the temporality of the chronic health condition is managed at macro and micro scales.

The findings demonstrate gendered differences in the chronicity of HIV. The period between diagnosis and ART treatment reveals that more male than female participants faced several medical challenges and experienced complex interactions with other people. Women participants in the study appeared to have adapted more easily and faster than men to the medical-related hardships of being on ART. Also, women were more concerned with medico-social demands than men in this research.

Complex treatment needs were associated with the iatrogenic nature of ART in relation to age and gender. Men tended to have a different trajectory when it came to chronicity, in that they got tested later and when sick, whereas the chronicity of women was based on being tested when well and much earlier – another reason that women were long-time survivors in the sample here (see appendix six). The results on general perceptions of health and illness confirm the chronicity idea that illness is an experience that is mediated by biomedical or clinical forms of culturing in a given time period.

The management of HIV chronicity shows a primary need to stabilise physical health first, in the short term. In this view, the self-description as being diseased but not ill is perhaps about functional health, similarly to other diseases such as certain cancer strains. The description of a ‘normal’ life by participants relates to functional physical health and the medical progression of recovery, as shown by Sabina (2013), which does not include psychosocial or social factors over time. Therefore, use of such phrases as ‘things were bad when I just started ART’ signify chronicity with both a biomedical and a biosocial characterisation of the normative period between HIV testing and throughout treatment.

The long period of time taken by the majority of participants to integrate and realign to medical care created the possibility for learning self-management skills in HIV. Thus, everyday ART administering by individuals made HIV fundamentally ritualistic, a chronic condition that could be perceived either negatively or positively. Talking about this issue, Lilato said:

Lilato (Female, 42): Sometimes I hear comments like these days HIV positive people die whilst very fat. [...] It is a deadly condition. I would love to die in a good way instead of being in this condition.

Stories about cure were connected to HIV chronicity, since it requires long-term biomedical care. Based on the remarks above, it appears that there is some religious condemnation and prejudice about dying from or with HIV, due to socially and medically preconceived perceptions of being on ART. HIV chronicity can perhaps be associated with illnesses such as depression, which contributes to social isolation and consequently the tendency towards non-adherence to ART, as also found by Uebelacke et al. (2015). There is a close temporal association between the period of living on ART and HIV disclosure. Consider Maata, who remarked:

Maata (Female, 46): It [disclosure] has benefited me because I can go anywhere, talk to anyone, because people cannot talk about me. It has helped me to live positively. When I feel hungry, I can tell the people I am with that the drugs are causing me to be hungry and I need food. They know my condition, because I am free. It has helped me mentally because I am not afraid of anything. Psychologically I am free.

The physical focus of medicalisation substitutes for psychosocial factors. But disclosure, as shown by Maata, allows projection of the self into the public, without fear of stigma but rather expecting support. HIV temporality functions as a basis of social factors, time management and professional life. The notion of chronicity is developed further here to involve gender differences in experiencing ART, adjustments to bodily limits, social changes, the management of disruptions and medication routines. Similarly, HIV temporality is extended in meaning to involve (re)learning and allowing the biomedical order to define everyday life experiences whilst attempting to build trust (in the medicine and others) and having control over personal health choices in the long term, as found by Bell et al. (2016).

The findings here suggest that chronicity must be related to differential historical moments as well as generational differences among people living with HIV. Therefore,

HIV citizenship makes the present health condition relevant, as the future in chronicity is shaped by past imaginings of ART and living with HIV – representations which were hard and difficult to reflect upon for the majority of participants.

#### **6.4 Discussion: importance of interconnections between themes and conceptual frame**

This research has established that HIV treatment is normalising physical aspects – for example, weight, pulse, viral load, blood pressure, basal metabolism, and many more variables ascertained by statistical means to be normal, as found by Flowers et al. (2012). By bring medical conduct and the management of bodies into a network of medicalisation, HIV governmentality through ART is prolonging lifespans. However, HIV chronicity prohibits and interrupts social, economic and political actions. Additionally, increased access to free ART not only creates a network of biomedical communities but also transfers responsibility for health from the public to the personal, similarly to results by Nguyen (2010). Although the emphasis on health outcomes in the wake of structural adjustment programmes, as noted by some participants, transforms health provision into more of a private than a public matter, HIV remains a public health concern under the control of state agencies and other stakeholders.

Understanding the chronic nature of life on ART appears to be a basis for co-construction of HIV identities for most participants. The findings have shown that biosocial modalities of HIV position the self from a wider viewpoint of social identity. The idea of real and imagined HIV communities points to efforts to legitimise membership and acceptance of equals within a biomedical sense of ART governmentality. Since ART improves physical aspects, it allows social acceptance as reflected by Goffman (1963), prevents powerlessness in HIV chronicity, and avoids stereotypes associated with group exclusion and social withdrawal.

Social identity takes in the direction of HIV sociality as presented above, because treatment practices and representations overlap around relationships, self-identity and abilities to live with HIV. Sociality is the basis of meaningful discourses of self-identity, exclusion or inclusion in a community through either self-care or group care, as shown in work by Whyte (2015). For example, being part of a group of males who are all HIV

positive in the Western province, named Club Z, illustrates the nature of interaction based on HIV biomedical traditions, which in turn create a sense of belonging.

The reported ways of dealing with the effects of ART confirm that HIV governmentality goes beyond the medical. Based on participants' stories, the social and psychological phenomena of conduct on ART have been mixed together and left as a non-medical problem in most debates on HIV and well-being in practice. For instance, the notion of disability in my findings is about disruptive side effects that make some participants dysfunctional through such issues as reported memory loss, dizziness, and the need for everyday medication at a specific time. The findings have shown that it is the strain on roles and the disruptions to daily routines associated with biomedical control and HIV chronicity that are limiting, as shown by Whyte (2012).

The findings on motivation partially support the idea that being on ART permits one to do some but not all things. This is due to the fact that medicalisation, as a process, does not entail that people living with HIV are actually medically fine all the time. That is why stigma has been transformed into different forms in relation to ART. People can be stigmatised not only for being HIV positive but also for weight gain and bad skin tone as well as failure to respond well to ART. This contradiction between the medical and social aspects renders problematic the clinical and popular assumption and claim that one can have a 'normal' and 'healthy' life when on living on ART, as also pointed out by Squire (2013:67).

Chronicity and temporality intersect, as they can be related to understandings of ART advancements and generational differences in HIV experiences. Although HIV chronicity modifies life and can be a disabling condition in some situations, it is the temporality of ART which through physical health improvements allows people living with HIV to live and carry on with their duties, as also described by Persson (2013). Stories of positive health by some participants constitute a shift from demands for a cure to prevention of further deterioration of the body after an HIV diagnosis and throughout treatment. The chronicity dimension confirms that identities in chronic conditions are based on 'representations of pastness' in illness and health (Tonkin, 1992; Ahearne, 2016). This study extends the theory of chronicity by adding that it is concerned with the present as well as the making of repeated stories of abjection by

participants so as to correspond with projections of present possibilities towards the desired future state, especially in terms of physical health.

HIV chronicity is associated with invisible mental health issues that are both biosocial and biopolitical. In the findings, it is the medical uncertainty that delivers a sense of chronicity when it comes to life with HIV. This is described as socially and medically hard to manage due to expectations of living a medicalised lifestyle, as articulated by Williams and Gabe (2015). Participants recover from physical health deterioration but still are faced with mental distress associated with HIV treatment, which means (re)integrating with others after diagnosis or long sickness, as also found by Adams et al. (2016). The longer some participants lived on ART, the more mental health challenges they encountered, rather than physical health difficulties.

In contrast, sociality shifts HIV chronicity in the direction of a biomedically formed sense of self and group identity patterns in the long term. Personal medical interpretations of the past shape future well-being and health conditions through bodily representations that depend on time and physical space, similarly to findings by Weaver and Mendenhall (2013). The concept of chronicity reveals that people with long-term illnesses focus on the future, which makes HIV temporality draw on historical and past illness experiences, upon which self-care interventions and health service provisions are based.

Social identities are interrelated with the sociality of HIV. For example, stigma being transformed connotes a sense of temporality when it comes to HIV, comprising different stages of health representations for a treatable but not curable pandemic. Each stage of HIV chronicity seems to manifest a different form of vulnerable identity; this challenges the idea that treatment can eradicate stigma in HIV, as shown by Bonnington et al. (2017). The way participants engage with their ART care and experience of services is shaped by the interactions they have at the hospital with peers and health personnel.

HIV governmentality constitutes elements of power and language in biomedicine. Experiences of being on ART are not linear, but are parallel to bodily responses and to gaining control of one's own chronicity for a healthy life. The concept of temporality is

in tandem with HIV biomedicine stages from diagnosis to treatment (Benton, 2017). Each of these stages needs specific medical normalisation, which is problematic, as complex treatment needs and mental distress over time vary based on gender, age, socio-economic status and state of physical health prior to commencing ART among people living with HIV.

Teachers in Zambia generally avoid discussing issues about HIV biomedicine, due to a common culture of shame and stigma. Nonetheless, ART's chronicity effects can perhaps be empowering in some circumstances, as the governmentalisation of functional health makes HIV positive teachers share self-care information and establish biosocial identities that mainly manifest in private spaces, as is the case with the groups of participants identified here.

## **6.5 Chapter summary**

The chapter has presented a second-level thematic analysis of the results. Here, the themes of biomedicine, sociality and temporality have been discussed in relation to the findings. How the identified themes interconnect with the key concepts of identity, governmentality and chronicity has also been explored. For example, the biomedicine theme confirms the idea that the health representations of participants do not include psychosocial issues in HIV governmentality.

Additionally, it has been established in this chapter that the relational and medically framed sociality of HIV has some resemblance to temporality in the management of life on ART. Thus, sociality as a theme contextualises social identity through the collectivised view of HIV as a societal challenge that affects everyone. HIV sociality, when linked to the philosophy of *ubuntu* in illness, expands and provides the opportunity to analyse individual narratives whilst looking out for shared experiences of living on ART.

In the next chapter, I situate therapeutic citizenship's interplay and implications for national development, *ubuntu*, and the decoloniality of biomedical knowledge and practices. A more discursive thematic approach than the description of results is broadly conceptualised.



## Chapter seven

### Therapeutic citizenship: national development and *ubuntu* in the context of HIV citizens

#### 7.0 Introduction

This chapter aims to explore therapeutic citizenship's framings in the study data and their implications for national development, drawing on both chapters five and six. It also examines how representations of therapeutic citizenship interact with *ubuntu* traditions about HIV in the data. The previous two chapters presented the first- and second-level thematic analysis of the findings. Here, I will undertake another, third-level thematic analysis by engaging the study results, particularly as analysed in the prior two chapters, with theory on therapeutic citizenship and national development in Zambia, to take forward both the analysis and the theory.

I am drawing, in this chapter, on specific initial themes from chapter five, such as participants' general accounts of illness and health, representations of HIV diagnosis and treatment, managing the effects of being HIV positive and ART, disclosure, support structures and professional life. Also, the chapter is driven by the three main sections of chapter six on biomedicine, sociality and temporality. These chapters feed into the five thematic categories below through a discourse inflected thematic analysis informed by structures of power and language.

This chapter has five sections. The first explores participants' notions of medical governance, and analyses the progression from medical to social aspects of therapeutic citizenship. The second describes connections between therapeutic citizenship and participants' perspectives on active citizenship and professional life. The third sets out how *ubuntu* traditions relate to HIV within participants' medical and psychosocial notions of collective responsibility for individual health in society. I also demonstrate the tension in participants' representations between indigenous and modern ways of governing chronic health conditions, and this tension is explored by referring to elements of decolonisation theory. The fourth section locates therapeutic citizenship's implications for national development through the lens of *ubuntu* as it relates to social and political capital. In the fifth and final section, I make the proposition that ART creates differences that are biomedically and psychosocially relevant for therapeutic

citizenship status. Through participants' framings of HIV and *ubuntu*, I also show that this form of biosociality connects characteristic identity framings within African – in this case, Zambian – culture with long-term effects for national development in the contemporary HIV context.

As we will see in this chapter, the three meso themes shown in the previous chapter demonstrate a therapeutic citizenship status which participants presented as theirs. This representation of ownership of HIV as a condition has broader implications for citizenship, including health or biomedical citizenship, and medical and social governance. In the next section, the biological and social framings of citizenship in the HIV context in Zambia are discussed.

### **7.1 Therapeutic citizenship in Zambia: from the medical to the social aspects of ART**

The difference between HIV diagnosis and treatment initiation, for many participants, was essential in bridging the gap between diagnosis and available effective treatment. The period between 2004 and 2010 marked the beginning of successful HIV treatment rollout in Zambia. The late 2000s saw the rise of the provision of daily medicine for HIV, including among government employees such as teachers, as more and more people tested positive. The big increase in ART access seem to have also been later, in 2014, based on this study's sample (refer to chapter two and see appendix 7). So there are historical and HIV-generational differences in therapeutic citizenship in Zambia's 'muddled' treatment era – a finding that has not been previously addressed in the literature, despite awareness of the significance of these different generations.

The treatment of HIV seems to be a public health strategy that reshapes individual, social and also national identities. The politics of HIV treatment is part of the more extensive and increasing biomedicalisation of citizens; but in southern African countries such as Zambia, ART, most recently within the 90-90-90 framework, is one of the principal drivers of such biomedicalisation. Self-governance is about compliance with ART, which plays a critical role in medical, professional and personal relationships that are health- or illness-negotiated and enacted. With new Zambian HIV infections standing at 48,000 every year (UNAIDS, 2018), the effects of being on ART are no longer about individuals; it is a public health and a social issue. HIV in this ART era has

shaped how citizens and the state apparatus negotiate health and social lives. Societies in Zambia have been transformed by HIV through taking medicine every day and on time – a continuity of biomedical care shared with other widespread chronic conditions (Rhodes and Pararini, 2016) but experienced particularly strongly and commonly around ART.

Since citizenship is about relationship between state and individuals, a sense of identity construction through interaction among members of a community as well as public engagement (Marshall, 1950), here it is inspired by being ‘medically reliant’ and the unending practices of daily medication, as described by Lutangu:

Lutangu (Female, 40): The medicine has become part of me, and I don’t really feel that I am bound or anything like that. It’s not a burden to me but something better, that’s the way I look at it. It is not a burden to me. [...] It is very important to me, because after finding myself in this situation, the medical practitioners thought it was best to put me on treatment, and it has been [in the long term] of help to me.

The transition from a focus on HIV prevention to an emphasis on ART in policy reveals the different phases of the pandemic. In this regard, the government of Zambia’s health policies are a direct form of citizen control using biotechnologies. For example, in 2015, the state introduced mandatory HIV testing for all individuals who go to hospitals and other government health centres for the treatment of any illness, on the grounds that early access to ART, now generally available, produces the best health outcomes. This policy also fits with UNAIDS’s 90-90-90 by 2020 targets, the first of which – to achieve diagnosis for 90% of those who are HIV positive – drives the second two, which relate to treatment and viral load suppression, a state that should indicate good and stable health but also untransmittability, hence working as prevention. The policy was received with mixed reactions, especially from civil society organisations who argued that no citizen should be forced to test for HIV (Mwanza, 2015). Although state policies highlight the value of HIV prevention and treatment efforts, the weakening of consent for testing and perhaps also treatment is slowly changing the meaning of citizenship in terms of rights and freedoms in Zambia. In the light of successful ART,

citizens must now accede to HIV testing (and treatment if positive) in order to access their health rights – a particular version of HIV therapeutic citizenship that affects people of all statuses. Illustrating the above, Mutukwa commented:

Mutukwa (Male, 39): There was a mobile clinic in my area, and I decided to go there instead of going back to the hospital, thinking they might have special drugs that they would cure me. When I went there they drew some blood and told me to wait for 20 minutes. I did not know what they were testing for. While waiting, I started wondering what the test was for, and almost ran away at the thought of being told the test was for HIV and I was positive. After 20 minutes, I was called back in and the counsellor told me to take a seat. He started talking to me, but I was not happy with the counselling because it was very badly done. [...] He just said, ‘you are HIV positive, so you should go to the hospital so that you can start treatment’. I went back home and vowed never to go back to the hospital.

From the findings, therapeutic citizenship, with its assumption that biological conditions and their medical amelioration and control frame subjecthood, shape public life (Petryna, 2004) in Zambia as well as individual and collective claims made and based on medical needs (Nguyen, 2008). The medicalisation of communities and specific groups such as teachers in the given spaces of schools is transforming the nature of social and professional interaction. For example, Emonda commented:

Emonda (Female, 35): I was not going to manage to be teaching or working [doing chores] at home if it was not for the [ART] drug. At least taking the drug has helped me to stay healthy. [...] Though when it is time to get more drugs in the middle of the term it becomes challenging. Some administrators are not approachable, they might not be HIV conscious, and so you need to lie and say ‘I am sick’ so that you can go and get medication. [...] As a teacher, if you are posted to a school where you have to share a house with a friend who is not HIV sensitive, it becomes difficult to take

medicine publicly or to disclose to them.

In the above remark, there is a dual dimension to therapeutic citizenship which is positive in the medical sense but negative in the social. So representations of chronic illness are multilayered: from the medical, people move onto social practices that can be institutionalised (as with testing) or informal (as with interpersonal relations). It is these social paradigms of interaction that define therapeutic citizenship within illness contexts such as clinics, and everyday health settings such as neighbourhoods and communities. Of particular significance is the fact that health challenges or statuses are perceived as hospital issues and cannot be discussed outside the medical environment. It is common practice to take medication at night for reasons of both medical and social interaction – for instance, side effects are easy to avoid when one is asleep, and there is no disruption to the daytime routine. The power to decide when to take ART was mentioned by Emonda:

Emonda (Female, 35): When I realised that it had those side effects [feeling dizzy and dryness in the throat], I decide to start taking the drug before going to bed at night. At least whatever side effects that are there would happen while I am sleeping. I have always avoided taking the medication during the day when I am working.

Since HIV citizenship is a long-term though medically manageable condition, its governance can be problematic at times. In the extract below, Nalu views her condition in a negative way due to challenges that relate to the frequency of taking the pills, which is restrictive sometimes:

Nalu (Female, 31): Just that living with a virus every day is a challenge, I can't deny that again. Maybe I will contradict myself, but there are times, like I was saying, I cannot say I am a normal person like the other person, I have got limits, what the other person can do, me I would say [...] if I do that maybe I would weaken my body. I have to keep my body like this, I have to keep my body like this.

The quote above – particularly the words ‘I cannot say I am a normal person like the other person’ – reflects some notions of Foucauldian biopower and biosocial elements. Being on ART is about imaging the self and others; hence when medical practices are not incorporated into social life, manifesting an HIV identity becomes hard, and problematic to relate to collectively. The body is portrayed as estranged, as in the above quotation from Nalu, resulting in a restricted HIV sociality predicated on a medical appropriation. Now and in the below, I move to the social aspects of HIV citizenship.

HIV socialities have overlaps between biomedical and biosocial factors that influence being a therapeutic citizen. For instance, the social limitations of normalisation through ART medicalisation, perhaps for all teachers, were the basis upon which some participants discursively segregated and potentially stigmatised themselves with the Club Z designation (see chapter five). The biomedical understanding of therapeutic citizenship was also shaped by HIV positive support groups, without any need for a medical professional’s involvement, particularly for those who viewed their therapeutic citizenship more positively, as commented on by Maata:

Maata (Female, 46): When we started the ARVs in 2004, there was a very high stigma in the district. People used to laugh, but we would just go and talk to them. We would tell them that one day, even though they were laughing at us, it would affect them. Even at this school there was stigma. So I talked to my friends, seeing that people were dying and were on and off [ARVs] most of the time. I talked to my friends in the support group, we talked to the teachers, and they started opening up, and others have gone for tests.

Failure to meet, identify and associate with HIV positive individuals is a basis for social withdrawal, solitude and anxiety. Living on ART and feeling alone has the power to initiate social self-exclusion and mental distress, as Milimo commented:

Milimo (Male, 30): I am not free with anyone. Sometimes I even feel like being alone and not in a group of people. [...] To avoid being discriminated by others. I would rather be alone than with people.

ART is a means through which biosocial alliances are formed. The results from the study support the idea that disclosure is hard, but it can be stronger and more useful when done among peers who are also living on ART than among those who are affected but HIV negative. The creation of alliances gives a positive sense of therapeutic citizenship. On the strong information-sharing alliances created between participants and other HIV positive individuals, consider Ngolwa's words:

Ngolwa (Male, 52): I have a friend here, that friend has opened up with me. It is not easy to open up, but with him, we share notes, because he is also on the same. We read and do some research.

The phrase 'because he is also on the same' exemplifies the coded language often used in HIV citizenship representations. However, as mentioned earlier, not all participants presented themselves as medicalised therapeutic citizens in a positive way. ART experiences differ within HIV citizenship but are generally a vital element of therapeutic citizenship. And when attention is paid to HIV representations, identifying with others who are also on ART invokes specific practices, and authenticates the biosociality of HIV treatment.

Participants' counter-narratives to this hegemonic citizenship story, moving between medical and social structures, created an entanglement of normalcy and a fragmentation of self-identities on ART. First, it appeared that collective as opposed to individual formulations of a 'normal life' influenced participants' representations of their social contexts for living on ART. This societal as much as 'treated' basis of normalcy was mentioned in an extract from Mweetwa to which I return below:

Mweetwa (Male, 42): I feel the mind is supposed to function normally [to be healthy], but according to what society has perceived as to what is normal, if I go contrary to that, they will say I am ill. So, in simpler terms, illness is doing things that are against what society perceives to be normal.

The above description of illness shows the strength of the social context of living as an HIV positive citizen. Dissociating social attributes from biomedical elements does not

support the idea that HIV medicalisation is the basis of normalising ART without being questioned. For example, Squire (2010, 2013) does not suggest that medicalisation can normalise, but that it is supposed to and it is being treated as if it does, in policy discourse, yet this supposition is problematic for people living with HIV themselves. For 31 participants, including Mweetwa, medicalisation was not the issue; medicalised social perceptions, rather, were what they had to position themselves with or against.

Therapeutic citizenship was not however positioned as only related to the biomedical and the biosocial; participants' current modes of self-governance also took into account their more specific social histories. Twelve participants talked about beginning their careers earlier in life, and believing that they had contracted HIV through their position as teachers with a combination of economic and social privileges. These variabilities across class and other social contexts have not been considered in considerations of therapeutic citizenship in the existing literature so far. As indicated in Muna's account:

Muna (Male, 42): From my early 20s to early 30s, I was a bit childish. This time I am mature, I am 42. I started work [as a teacher] pretty young, at the age of 22. But I started working at 19, having completed school at the age of 17. That period, from about 19 to early 30s, having a job and a salary, I was carefree [with concurrent sexual partners]. Now I have toned down.

Participants with positions in schools created opportunities for pastoral care that made HIV citizenship a positive thing. Consider Moola's remarks, cited again here, which significantly showed the collectively organised, communal attributes of HIV citizenship:

Moola (Male, 51): I organised the teachers who are living positively to get together. We went for training on Care International concerning HIV and AIDS. The guidance teacher organised for us to go for this particular training. I was a pioneer of this programme. We were told that if we tested positive, we had to access to treatment. We were told if we adhered to medication, we would live much longer. That was quite satisfying. I became an active person and spoke for people living

with HIV. I told the superiors that people that have HIV can work, they should not be sidelined. I would even talk to the DEBS and all stakeholders and was supported by these people. I had the privilege of sitting in the meetings with the DEBS and people in the administration to speak concerning HIV positive teachers. During this time, I remember my health went down. But I continued speaking on behalf of HIV positive teachers, telling the administrators that HIV positive persons can also take up leadership positions.

The above quote reflects contemporary Zambian HIV therapeutic citizenship's elements of recognition, mobilising, activism and professional life consolidation, which go beyond those discussed in other contexts (Nguyen, 2008; Patterson, 2015). Participants who were in positions of power in schools provided examples of how one's own HIV positive status increased one's efforts to campaign for better work conditions, especially for teachers living with HIV, as they had one principal commonality that tied them to this group of people – namely, living on ART. The 'republic' is constituted by heavy individual and collective governance, outside of people affected by HIV, as is evidenced in participants' representations.

The discourse of a republic of HIV-citizenized persons is not about them being positive, but is about the treatment of the condition, which leaves the infected 'muddled' between being ill or healthy. The majority of participants valued this kind of citizenship both positively – particularly where they presented it as part of a national project of commitment to treating HIV positive citizens, their treatment, and maybe themselves as teachers also – and negatively, particularly when they had problems themselves with ART or stigma, including at work. The arguments about the duality of HIV therapeutic citizenship above are also evidenced in chapters five and six.

This research has established that being HIV positive and on ART in Zambia can create a specific form of therapeutic citizenship. This form of citizenship is evidenced in the findings by aspects of generational difference, compulsory testing, social understandings of illness, ART compliance, clinics, HIV's medicalisation as a 'clinic issue', professional lives, and intersectional issues around especially class, that suggest

a dual representation of living on ART for the majority of participants. Therefore, the findings constitute a critique of the ‘post-AIDS treatment’ idea of Tsampiras (2017) in South Africa, since some people are only quite ambiguously within the treatment era, but at the same time are living in that era long term and with some normalcy, as well as having many other social identities playing out within their lives.

Characterisations of otherness when on ART broaden rather than, as might be expected, narrowing representations of the prospects of enjoying therapeutic citizenship privileges. Difference and otherness, as presented in the findings, are central to the process of legitimising hardships and seeking normalcy of HIV citizenship. In this view, therapeutic citizenship is characterised by two main contradictions of otherness: the first is the need to resolve continuous public and self-perceptions of being seen and treated differently from those who are HIV negative, especially for women; the second is the normalising aim of dissolving all forms of otherness, which takes away the extra privileges of being HIV positive, across genders, while restoring ordinary personhood. In the same vein, some HIV organisations that ensure the rights of people living on ART are intensifying civil society’s role in creating and validating HIV identities. For example, this research found that the activities of such organisation as the Seventh Day Adventist and Catholic Churches and the AATAZ focus on the welfare of those living with HIV by meeting individual needs first for the common good. As previously cited, Emonda’s HIV status had led to an offer of college sponsorship:

Emonda (Female, 35): I have received support from the church. I have received food supplements. They would get people who are positive and supplement their diet every month. I also got an opportunity to get sponsored to do the teaching course through the church.

My results reveal offers of scholarships to train as teachers from church organisations for some participants. Eligibility for these reported scholarships meant that an HIV diagnosis had benefits and privileges that those who were not on ART were not entitled to; hence therapeutic citizenship status rendered individuals active members of society while being distinguished from others on the basis of HIV socialities (Squire, 2013; Whyte, 2014).

Participants' claims to be treated properly at clinics 'as teachers' can be associated to this class and other social positioning of HIV citizenship. These claims were gendered in that it was mainly male participants who spoke about being teachers and needing special treatment. In Zambia today, the HIV and ART situation appears to have extended self and communal governance from prior arguments about medical and social aspects of therapeutic citizenship for the public.

The above discussions confirm a complex progression from medical to more social aspects of therapeutic citizenship. This progression is noticeable not just in the forms of citizenship appearing in the representations, but also through language formulations in the results – such as 'living with HIV' rather than 'being HIV positive', and people with 'compromised immunity' not 'HIV patients' – which reiterate how language matters in HIV identity, as also found by Dilmitis et al. (2012). Other language aspects are referred to later in this chapter.

Political actions at any given level play an essential role in making people living with HIV either passive or active citizens. The section below describes the connections between therapeutic citizenship, the politics of professional life and aspects of active citizenship.

## **7.2 Therapeutic citizenship ties to professional life and good citizenship**

The link between teaching and ART lies in its enabling power to improve physical health, which then allows HIV positive teachers to work. Since ART prolongs life, it allows individuals to continue in their profession and be 'good citizens' in this respect. Medicalisation in this view retains individuals with job experience within the workforce. For example, teachers who have been teaching for an extended period in the sample have work experience that is useful for learner achievement and school completion rates – an aspect that was impossible in the pre-treatment era, as HIV mortality and physical health deterioration increased teacher absences in Zambian schools (see chapter two). Teaching expertise and skills development are associated with the period of practice: the longer teachers who are on ART remain in their job, the more experienced and productive citizens they become, as Maata mentioned:

Maata (Female, 46): This time with the use of the ARVs I am very strong. I have

noticed that those who are negative and not on ART sometimes do not even come for work, but in my case, I come for work every day. [...] This time, even if I feel sick, I can still come for work. Previously, when I used to be sick, I would stay home. This time, even if I am sick, I come and work, then go home later to rest.

ART's workings in the findings relate to enabling participants to teach and carry out other duties after recovery. The significance of therapeutic citizenship for the profession and for being good citizens is also embedded in positive teachers' abilities to relate well among themselves rather than with negative teachers – that is, if they know or are open about their status. In Nandi's requoted remarks below, being a good citizen is about adherence to ART and learning from the negative consequences of defaulting on 'taking medicine' – a feature of HIV citizenship:

Nandi (Female, 54): I have seen some people who disrupted taking the medicine and they died like animals. Being the head teacher is a testimony to me. I tell those that are positive to just take the drugs.

HIV solidarity and empowerment of others by long-time HIV survivors is a tenet of good therapeutic citizenship for these participants. Therapeutic citizenship is about empowering others, as well as flourishing oneself, and this sense of being a good citizen is an outcome of effective treatment for HIV. Being on ART and living with HIV can be used to organise HIV communities and to educate colleagues. The ability to represent others who are also HIV positive has some therapeutic citizenship relevance, as it exemplifies an intrinsic sense of belonging. However, some participants who were leaders in schools expressed concern about the reluctance to disclose the HIV status of their colleagues to learners, as can be seen in Mutukwa's remarks:

Mutukwa (Male, 39): To be truthful, I am aware of colleagues that are living with this condition, but that is not a common topic people would want to share [at work], we don't usually do that.

Predispositions to exchange HIV care between learners and participants denote a strong tenet of therapeutic citizenship in this context. Learner-teacher relations mediated by therapeutic citizenship status can appear problematic when a teacher is known publicly (by parents) to be living with HIV and/or when a learner is HIV positive. However, only two participants stated that they were stigmatised by some parents who had demanded that an HIV negative teacher teach their children. This encounter with parents preferring HIV negative teachers describes a form of stigma that is demotivating for teachers living on ART. Four participants mentioned that they had good working relations with parents and pupils, despite public disclosure of their status. This social acceptance has psychological benefits, even though it neither guarantees an end to stigma nor increases prospects for helping learners with HIV. For example, Emonda commented:

Emonda (Female, 35): Some children are born with HIV, and teachers sometimes stigmatise such children because of lack of information concerning HIV. Such children should be supported. [...] There are times when parents would disclose the status of their children, and sometimes teachers would discuss the child's status and the fact that they are on treatment. [...] I feel a connection for sure. There are instances when a child would be brought to school and we would be informed that the child is a double orphan who lost parents to HIV/AIDS. There was a teacher who could not handle that child because of knowing the parents died of HIV and AIDS. [...] A teacher is a parent away from home, and so they should have the knowledge to sensitive children. Children trust teachers, and even more than their parents sometimes.

The excerpt above's emphasis and positioning of a teachers as a 'parent away from home' in relation to the HIV affected child is enabled by Emonda's own status openness, connection and sense of care for especially learners who are also on ART.

One of the therapeutic citizenship aspects found by this research is informal networks, a feature of many kinds of citizenship, that seem to sustain HIV therapeutic citizenship among this participant group. It is clear in the results that participants used their diagnosis to associate with peers, and they spent time with each other as well as making

visits to the homes of their colleagues, especially those housed within the school premises. This was noted with a group of three female teachers (all participants) advising another HIV positive colleague, who was not feeling well, on best health practices. However, positive teachers in some cases seemed isolated, shy and uninterested in any form of general discussion, even on non-health related topics, with colleagues in school staffrooms. Also, some HIV positive male teachers used the phrase ‘Club Z’ (cited earlier) to refer to being on ART – a name borrowed from a local telecom company; this implied a ‘top-up’ with reference to airtime (credit), but its actual usage by these teachers was ‘topping up on life’ (prolonging life) through ART drugs. While this phrase could name a positive social association between people, it also could be said implicitly reduce life and citizenship with HIV to a marginal extra. The above findings describe forms of HIV socialities that enhanced a sense of shared critical HIV citizenship, as shown not only by elements of self-care but also by teachers being caregivers to their HIV positive learners, as also shown by Campbell et al. (2016) and Persson (2016). Nonetheless, the above go beyond Campbell et al. and Persson’s studies, by showing the ‘muddled’ position that teachers find themselves when living with HIV and supposed to be carers and supportive to learners who also on ART like them.

ART is not just about control of HIV, but is also part of the social and political infrastructure for good citizenship in a high prevalence country such as Zambia. HIV/AIDS activism and power-brokering activities are present at local and international levels. There are national movements that appear to have created both active and passive citizens through HIV representations. Based on the results, the HIV treatment process is reducing differentials are reducing, but the HIV status for those who are positive does not change. For example, those with more relative views about the pandemic, and perhaps individual under-recognised problems with HIV’s medicalisation and normalisation, are struggling for membership between the two groups. The results seem to say, that some people become included within therapeutic citizenship – despite its difficulties or ‘muddle’ – and that some are in a sense ‘immune’ to it and not part of it, probably based on their own individual medical/stigma difficulties with ART. From the first group, for instance, Silishebo alluded to her own practices within a notion of good citizenship, that also extended to work with people of negative and unknown status:

Silishebo (Female, 49): I would love that I joined an NGO which deals with ART, counselling people, I have helped a lot of people. Most people on ART here know me. There are times I would come across someone who looks ill and I would be called upon to counsel them. I know the tactics to use to get the person to get tested where others would fail. At least I have made so many people accept their status.

The political nature of therapeutic citizenship is shown in the state-citizen contract and the roles of NGOs in HIV. The role of government in HIV treatment services is sometimes undercut by the work of NGOs. The state does not provide services beyond the supply of ART, yet NGOs continue to mediate within an informal economy of psychosocial resources for living with HIV. Hence, claims and entitlements to ‘biological citizenship’ beyond medication are limited to humanitarian social welfare, without any legal criteria that recognise the status and privileges of being a therapeutic citizen in a social as well as a medical sense. The role of NGOs through community health workers was found to cultivate supportive conditions for people living with HIV, away from the hostile environment of the workplace, at hospital as well as home. Therefore, in the section that follows, HIV citizenship is explored by situating *ubuntu* in relation responsibilities for health and illness, and by also relating some findings to elements of decolonial theory around medicalisation.

### **7.3 Recasting HIV citizenship through *ubuntu* and elements of decolonialisation**

Traditional medical knowledge and methods for dealing with illnesses seem threatened by Western medicine’s focus on the individual in the treatment of HIV. The findings show that the management of a chronic condition such as HIV includes technologies of the self. Yet *ubuntu*, previously discussed in chapter three, an important philosophical concept within southern African societies and cultures, which refutes the idea of a single subject, was also embedded in the research material. Participants reported *bukuli* (a word from the Lozi language which means ‘diseased’) as a way of recasting their HIV identity. The above term is in a Zambian language and shows *ubuntu* traditions being remade – here in the HIV context - through words, as shown by Ratele (2016) and Tarkang et al. (2018). By referring to concepts such as *kibakuli* (a Lozi expression used

to differentiate someone as part of a group of sick people), participants could then receive support from other members of their household or community. Hence, identifying as *mukuli* (in Lozi, singular for a sick person) can be associated with enhancing the health of the affected through language (Dilmitis et al., 2012). Although sometimes this can invite a sense of stigma, in the *ubuntu* context it fosters some level of privilege, special treatment, and care for, by and of others. This fostering is due to the extended spectrum of HIV experienced through family or friends, which translates into support, and acceptance of ART as part of wider living in a community. How people self-organise to solve health-related problems in communities without hierarchical or state interventions is central in the African tradition of *ubuntu*.

Standard practices of self-care required when living with HIV are often driven by collective action to improve health outcomes. Hence, *Ubuntu* -in the ART context- represents the changing face of individualised technologies of the self to capture humanistic ways of thinking, organising and living within groups (Ratele, 2016). Mutual recognition as being on ART is based on a long-term life-transforming medical condition and is used in negotiating an identity, which starts with crafting an image that fits into a subgroup or language, away from the mainstream, as evidenced by the use of ‘we’ in the results when participants talk about the self. In the light of the above, temporality in relation to ART followed the findings about the participants’ representations of the realities of HIV, revolving around a key triptych: being, becoming and belonging. Participants’ experiences of being on ART for a year or more seemed to contribute to their becoming therapeutic citizens through the undoing of previous identities, with a new sense of belonging to an HIV community that was either represented as socially imagined or medically real or both.

In contrast, even though biomedical interventions set up a code of chronic health management, *ubuntu* tradition also prescribes the governmentality of conduct towards illness, and sets the social ethics of good behaviour. In the case of HIV, rules of conduct prescribed by *ubuntu* establish the basis of either acceptance or rejection for those living on ART, as they can be breakers of a communal ethics of conduct, especially around sexual behaviours – the main source of HIV transmission. As Muna commented:

Muna (Male, 42): The reason is, in Africa and Zambia, when one is positive, people

always attach that to being immoral, promiscuous; they don't look at other factors that might have caused it. So, to avoid external stigmatisation, I prefer keeping it to myself. [...] Because even if society is dynamic, there are certain things it does not accept, like HIV. No matter how educated we can be, the element of stigmatisation is there. Others struggle with self-stigmatisation; I would not want to be drawn into that battle, that is why I do not come out to disclose my status. Because if I tell someone I am positive, the next question is 'how?' 'It's through sexual intercourse, then you are mischievous'. So, to avoid argument I keep that to myself.

Though *ubuntu* is being situated as positive, the excerpt above describes a failure of *ubuntu* or an aspect of it. *Ubuntu* is limited or double-edged when it comes to HIV, for example in Muna's account, disclosure can lead to either encouragement and acceptance or discrimination and condemnation.

This codification of conduct is a form of governmentality, framed around communities telling subjects, for instance, how to be humane by treating others with compassion and respect. Hence, *ubuntu* can assure a positive attitude from others for people living with HIV, which does not distinguish them from others on the basis of their status, as described by Pelekelo:

Pelekelo (Female, 37): People are always close to me, not because of what I am.

Because I look at them, and they are able to see in me that I have the potential to do anything. They even tell me that I can do better in life, given the opportunity. They don't really look at my condition.

Since *ubuntu* is a form of governmentality that inspires groups and individuals to share problems and act in concert with others, when it comes to HIV it might seem hard to collectivise the conduct of ART management. Participants in rural Zambia, like Pelekelo presented the meeting demands of ART as an affirmation of shared humanity through recognising the individuality of others living with HIV, thus resolving tension

between a general sense of solidarity and more of an individualised responsibility for ART care. *Ubuntu* tradition had a positive effect on eight participants from the rural location of Senanga District, as responses of acceptance as well as disclosure were higher among these rural participants than their urban counterparts. The incidents of stigma and discrimination that were reported by participants, like Muna, in the urban district of Livingstone were anathema to, and not a reflection of, the *ubuntu* tradition in relation to HIV, as also described in Tarkang et al. (2018).

*Ubuntu* in illness is not just about care but a common way of living. HIV research has often looked at activism and not at communal aspects of living on ART. This research found that self-education about HIV care is related to ways of living. These ways of living often incorporate Western medicine – in this case ART – so that they manage ART from an inclusive perspective (Letseka, 2012; Ratele, 2016). Hence, the concealment of HIV is situational and problematic. Individualism is related, in the study contexts, to the unity of being, which in manifestations of *ubuntu* is transformed to represent community values. For example, in the extract below, Sumbwa described what he considered to be unequal treatment received at the clinic. But contrariwise, the treatment might be part of equal service delivery to clients due to *ubuntu*, regardless of status or profession:

Sumbwa (Male, 39): Sometimes I am bothered. Because when I go to get medication sometimes, I don't feel welcome at the health centre. Sometimes when I go to the health centre I get exposed to a lot of people, and some of the health practitioners do not understand me as a civil servant. This is because some of these people that give us medicine are just caregivers from the community. Sometimes they do not handle us very well. I get delayed by the volunteers, because they do not understand that I need to get to work.

*Ubuntu* manifested itself, through acts of care for others and peer support, even at hospitals and during the collection of ART drugs. Although Sumbwa's account may reflect *Ubuntu*, it largely shows that middle- and working-class people in southern Africa – certainly in SA – complain about the conditions in public hospitals (Endicott, 2017). Having to wait a long time and to experience discrimination around HIV –

documented from participants' responses, in chapter five – is often due to bad/underfunded/undertrained medical practice, and not essentially *Ubuntu*.

The hospital might also be a platform through which the creation of social groups, collective power and identity for people living with HIV is experienced. Nonetheless, therapeutic citizenship can only create weak social bonds if the environment is hostile and there is lack of trust among clients and between healthcare providers. Therefore, therapeutic citizenship in the context of *ubuntu* is concerned with the interactions of people living with HIV in communities, though it can also extend to relationships between the state, health practitioners and people with HIV. There was status selectivity of social networking among participants but there were also community relations that were non-biological or not medically founded. Many examples of peer participation in formal and informal activities given in the findings show knowledge exchange about treatment practices within broad interactions in society between those of different HIV statuses. As Mwangala commented:

Mwangala (Female, 49): With my friends there is not much difference, because there are some friends of mine that I share information with, we share secrets and they know my status. We share information.

The different experiences of ART are the basis for the consolidation of the lived realities of HIV, which creates a consciousness of self, and collective evaluation – including assessments of long-term practices of daily treatment. However, forms of action towards the creation of a credible body of HIV knowledge seem to be creating some representations that separate 'them' and 'us' largely on the grounds of HIV status. This is a form of othering that cements therapeutic citizenship status. These various and sometimes contradictory engagements represent a source of continued critical citizenship. The necessity to balance social life without losing sight of the need to meet yet also resist the overwhelming demands of ART can be colonising, physically and psychologically.

The decoloniality of medical knowledge around HIV treatment is seen through participants opposing forms of Western medicine and reporting traditional or religious

ways of managing the body with chronic illness (see chapter five, Table 5.8). Though participants reported the effectiveness of ART, the search for information and use of local remedies whilst adhering to ART, was a continuous process. Life on ART does not just imply the governing of bodies, as shown in many studies on illness and health, but also creates spaces for new knowledge development, capabilities and lifestyles (Fassin, 2007; Masing, 2018). These spaces tend to conform to the societies that the affected people find themselves in, which may also prohibit the full expression of therapeutic citizenship status, which affect medical knowledge and information resources levels sometimes based on gender.

Accounts of gendering in this research seem to reflect a pattern of colonial order. From the findings, gendered experiences of HIV related more to the politics of family and were less about self-determination. Gender relations in participants' stories of life on ART mirrored colonial systems of power, and positioned women as 'property' of men. Women in this study claimed different relationships characterised by blame and pity, and emphasised a lack of independent choices about their HIV diagnosis. The subordinate position of women marks a long-standing tradition, predating colonialism, yet it can also be considered a tenet of colonialism and the grossly unequal gender relations instituted therein. The need and difficulty of decolonising structures of responsibilities, rights and traditional roles that are biased lie in the disadvantage they place on women socially (Smith, 2013) as well as medically when they are living with HIV, are evidenced by Lilato:

Lilato (Female, 42): He said it wasn't necessary and he would take whatever comes. But when I was diagnosed HIV positive, there was a lot of tension in our home and relationship. I do not know [his HIV status] if he tested, we did not do it [HIV testing] together, that's what surprised me. [...] My husband told me not to disclose to anyone, including the children. [...] My only fear is I have a partner and do not know how he would react to that. I don't know if it might lead to him divorcing me. I think if I were by myself [not married] I would have gone flat out disclosing.

From Lilato's extract, it can be seen that *Ubuntu* is gendered. The ways in which women are concerned with the welfare of others is more than that of men. Also, the obligation and awareness to be answerable to men by women regarding their health shows the gendered elements of *Ubuntu*. While most men were less obliged and concerned about the general wellbeing of their spouses, women were expected to be caregivers, to all affected individuals even in this HIV context, than men (Squire, 2010).

Additionally, socio-political practices situated in language create categories of therapeutic citizens. To some extent, universalising ART management and HIV information denotes coloniality. There is a connection between therapeutic citizens in the way that they organise, biologically connect, and distinguish themselves from other nationals in a country. There is a sense of 'othering' associated with Western medical interventions which suggest that people are xenophobic within *Ubuntu*.

While post-structuralists describe individuality, responsibility and autonomy as part of the Western medical culture, in the global South treatment practices affect the collective, as demonstrated by Doyal (2016). At a macro level, legacies of colonialism seem to reproduce themselves in various ways, even through medical knowledge and practices. For example, African states are most affected because of prevalence and are on the receiving end of medical advancements in the treatment of HIV, with direct repercussions on indigenous processes for dealing with pandemics (Turner et al., 2017). It can be argued that the absence of a cure and the presence of effective HIV therapy have created a systematic dominance brought about by pharmaceutical colonial processes, especially in ART procurement, for a country such as Zambia. – a situation sometimes called pharmaceuticalisation. Consider Mutukwa's statement:

Mutukwa (Male, 39): What I also want to say is I am wondering how those manufacturers of these drugs can fail to make a cure if they can manage to make this drug that paralyses the virus for 24 hours. I think a cure is available, but people are making money out of selling ARVs; that is why they don't want to give or release the cure. I think it is a business. I have a brother-in-law who is a doctor, who made a statement that a cure is available but kept away from Africa.

From the above quote, although global responses to HIV are progressive, and participants who lived on ART linked them positively to what the state and NGOs were doing with and for them, they also associated those responses with actions that formed colonial medical trajectories for individuals and low-income governments. The findings of this study show therefore how teachers living with HIV in Zambia map the complex processes of HIV subjectivity. Medicalised groups such as these may see ART as a form of neoliberalism, dominating low-income African countries by making states dependent on external help for ART, as described in chapter two.

At a micro and meso level, some participants see themselves as victims of pharmaceutical colonialism in Zambia, due to a lack of freedom in how they must operate personally, interpersonally and in relation to their local HIV clinics; and to and nationally initiated medical surveillance. Representations of control of citizens with HIV were not limited to ART but also includes behaviour patterns, dieting, and advice about drug adherence from doctors, nurses and other community health workers that comes with taking pills daily, without any cure in sight. Even participants with low HIV and ART and health literacy reflected a social awareness of ‘pharmaceutical victimhood’. Perceptions of pharmaceutical colonialism in this instance involved the impact of non-flexible disruptive HIV regimens on participants’ social and professional lives. The idea of pharmaceutical colonialism in this research is presented as part of participants’, and many others’, understanding of the continued hand of Western biomedical interventions in Africa, and Zambia in particular. The above perspectives, though not covered in research on HIV and ART in Zambia, it supports ideas of studies such as Nye (2003), Yach et al. (2004), Murray et al. (2013), and Young et al. (2019). These studies reveal the burden and disruption of biomedical practices especially on the social aspects of long – term medication.

Biomedicine is entangled in social elements of HIV through such factors as stigma. Social difficulties associated with HIV cannot be eradicated by ART effectiveness only. The medicine cannot be the only basis to ‘normalise’ HIV chronicity, without considering its high mortality legacies and treatment exceptionality in African nations. Results show that HIV is still seen as a deadly and incurable disease that has some cultural, social, economic and political – as well as medical – implications at various

levels (Moyer and Hardon, 2014; Squire, 2010). Hence, the decolonisation of knowledge here is embedded in the relationality of HIV management, through references to an awareness of interdependence and integral relationships amongst participants in the community of which they have become part. This relationality is about the search for balance and harmony while living on ART and with HIV. It was evident in the dialogue with participants that becoming and belonging while on ART were framed by coloniality and decoloniality respectively. Since decoloniality involves undoing practices that are not indigenous (Smith, 2013), there seems to be a connection between *Ubuntu* and decoloniality in some ways, for instance through people organising and retaining some traditional ways of living in managing illnesses, including HIV pandemic and its Western forms of treatment.

The act of (dis)entangling the psychosocial factors within the HIV community signifies the process of decolonising real (space), imaginary (power) and symbolic (knowledge) attachments to ART (Mignolo and Walsh, 2018; Masing, 2018). That is why therapeutic citizenship, as framed here, refutes the perception that HIV experiences are universal. The findings show that normalisation of ART has a Western origin which describes the global but neglects the local elements that are relevantly attached to ART adherence successes, as shown by De-Graft et al. (2010). The results suggest the importance undoing medical narratives of HIV normalcy and totalising claims about ART legacies. These narratives and claims typically see experiences of life on ART as universal, and stem from universalising and Western discourse and practices of pharmaceutical knowledge underpinned by geopolitics.

Therefore, decoloniality is a useful perspective for reframing therapeutic citizenship within the biomedical context of indigenous, ritualised and/or religious societies in Zambia. Although there are concerns among participants to (de)globalise the production and supply of HIV drugs away from Western settings, the related contexts of medicalisation and normalisation still must draw from overseas medical practices about the body. However, *ubuntu* is employed here to explicate the indigenous establishment and sustenance of HIV alliances and social relations. At the same time, although everyone appears to be involved in the well-being of others, support and acceptance involve various factors operating within/to split up *ubuntu* including gender, age, locality, and complex individual treatment needs. Self-descriptions of participants were

about their current condition, what they wanted to become, and where they thought they belonged in the HIV community and beyond; they were thus in or moving towards *ubuntu* in many cases. Hence, struggles to live with HIV and adhere to ART in the findings are linked to a need to decolonise medical practices and the related preference for indigenous treatment solutions by some participants. For example, Mutukwa's remark below shows the extent of a localised solution to an international problem:

Mutukwa (Male, 39): Here in Zambia I have heard about Sondashi – a formula that can cure HIV, but then it is taking time to be approved. So, I say to myself, 'maybe in the years to come it will be approved'.

The reference to an indigenous Zambian herbal HIV remedy called SF2000 (Sondashi Formula), which is not approved for use, appears to be part of the call to undo and thus decolonise current treatment regimens and origins. Mutukwa demonstrates a deconstruction of biomedical solutions by showing a preference for locally manufactured and approved treatment interventions. Additionally, the desire to have approval for local HIV medication, indicated by Mutukwa, is a sign of decolonising medical knowledge and the search for an alternative indigenous knowledge or solution. It is this search for knowledge within the local context that generates the decoloniality narrative within HIV research.

From the above, other concepts, such as socio-political capital, emerge as an extended framing of therapeutic citizenship. The notion of socio-political capital is useful, as it is central to mainstream development discourses. Insofar as teachers in Zambia have some level of ability to influence the public status quo, they enjoy socio-political capital. For those living on ART, socio-political capital is noticed in the sharing of material resources based on professional and social networks (Fine, 2003; World Bank, 2003). However, living with HIV and ART depreciate that capital in some ways. The effect of ART and HIV on capital is seen and discussed in the next section on the connections between therapeutic citizenship and national development.

#### **7.4 Therapeutic citizenship and national development: HIV, socio-political and economic resources**

As many Zambian citizens – including important population groups such as teachers – get medicalised through ART, there are wider long-term national development implications of the HIV epidemic for Zambia. These include the capacity and sustainability of its human, material and medical resources, particularly arising from taking an approach to HIV citizenship founded in *ubuntu*.

The overall burden of HIV ranges from social exclusion to economic inequalities. Responses in this research on social support denote possibilities to have social development without a thriving economy (Mehrotra and Jolly, 2000) – but only when institutions and the state set the right priorities, such as the sustainable supply of free ART. Since health, education and development interact in many ways, there is a connection between HIV therapeutic citizenship and national development. The link made here focuses on political and social aspects of therapeutic citizenship's implications for national development, exterior to the mainstream conceptualisation of development, which is often made in economic terms.

The findings here suggest that there is perceived by participants to be little attention to social sector expenditure but recognition of high priority on the political front for health provision is seen to be strong, primarily through ART access. The lack of state action in social and psychological interventions when it comes to HIV has seen the capabilities of professional groups such as teachers who are living with HIV weakened.

Maata, (Female, 46): We were lobbying the government to bring the ART to Western province. We would meet the directors and other people. This is because there were people who could not afford to travel to Lusaka for the drugs. [...] I wish the government could introduce some support groups in the schools where the positive teachers, or even those that are not, can talk and help each other in one way or another. It nearly started, but it hasn't materialised, maybe because there is no funding. [...] Talking about helped the group and I as an individual because I could learn what others were going through, rather than staying at home alone without being in a group. [...] We need support from the Ministry of Education so that those who are far can receive information about the virus.

Free access to ART is the only essential aspect of HIV care found by this study. Consequently, and since biomedical interventions do not offset extreme social and economic inequalities, the lack of psychosocial resources around HIV for communities is a hindrance to development at various levels. This singular focus of care on ART provision alone ignores the need for other specialist HIV-related health services. The absence of employment, social and cultural activities directed at or including health services around HIV that goes beyond ART in Zambia is also a social and economic constraint. Concentration on ART workings only by health personnel and participants themselves, also neglects the integration of relevant mental health services in local institutions –services which might then allow for people with HIV to experience more participation and empowerment within their local social worlds. Nonetheless, the discourses and practices of therapeutic citizenship, as explored earlier in this chapter, do take these issues into account, and could therefore promote national development, as shown by Jolly (2003) and articulated below.

Health and education connect as issues of national development. Therapeutic citizenship, within the *ubuntu* context and based on the findings here, often considers health and education as human rights, not necessarily in western sense, while neoliberalism's effects on health or education consider them as an investment with high returns – hence the commercialisation and marketisation of long-term health conditions such as HIV (Fukuda-Parr and Kumar, 2009; Squire, 2013). Across such conflict, there can be, as for many of my participants, mutual reinforcement in being a teacher on ART and contributing to national development. By recognising the connection between national development, education and health (see chapter two), therapeutic citizenship can ensure that rights are not just rights of individuals, but essential for yielding high economic, social and cultural returns for and through groups such those living with HIV – as shown in this research. This is because therapeutic citizenship creates conditions for participation, the moderation of inequality, and collective and individual ways of living which attempt to minimise the poverty associated with socio-economic hardship due to living with HIV and on ART.

Furthermore, ART has a double function. Participants were interested in the health purposes of the treatment, and not treatment as prevention, about which, in any case,

they knew little. More broadly, HIV's (re)medicalization, including through TAsP, rejects the social complexities of taking treatment as prevention. This marginalisation also shows the marketisation and neoliberal-driven response to HIV as a chronic condition (Ingram, 2013; Nguyen et al., 2011; Persson, 2016). Therapeutic citizenship for my participants, despite the important biosocial aspects of it, was fundamentally about biomedicalisation and pharmaceuticalisation, rather than biosociality. In other words, participants' lives are driven by ART, and are more centred on managing physical health through medicine than on social aspects of HIV-medicated bodies' reality in Zambia. More generally, the trend of relying on biotechnological solutions such as expansive and governmentalised ART discourses and practices, in both public health and everyday lives is not only to treat and prevent further physical deterioration and restore health, but also to govern the growing risk factors of HIV drugs, to control everyday chronicity, and to optimise functional health and hence, social and economic performance, and development (Dumit, 2012). Perhaps the negative aspects, for development as for individuals and groups living with HIV, of a biomedical regime that largely sidelines biosociality, could be addressed by understanding more fully, as do the participants, the place of ART in their lives and the nature of their therapeutic citizenship.

National development is associated with healthy citizens. The findings of this study support the claim that health is a precursor to national development. For example, with the biomedical intervention of ART, participants were able to work and feed their families, thereby contributing to their own self-development and that of learners and the country at large, indirectly, through knowledge exchange and development – and much more directly, through taxation. The health of individuals defines the process of national development, which perhaps depends on education and the health of teachers alike, in many different ways.

The community-based and multisectoral approaches that were reported by participants reflect a global and national response to the temporality of HIV, which is hard to manage with limited resources at the personal, local and national levels. This study found that living with HIV is made complex due to medical and social needs which require other material supplies like food, transport as well as comorbidities. The absence of these supplies can threaten citizens' potential capabilities, even whilst they are on

ART. This is due to varying requirements in addition to ART held by different HIV positive individuals and groups, distinguished by for instance class, gender, location, and level of health. These different material relations to ART can themselves affect national development in sectors such as agriculture, mining, health and tourism as well as education (CSO, 2014; UNDP, 2010).

The nature of relations between development, health and illness is diverse. Cultural, symbolic and social variables were found to be forms of resource in living with HIV for the majority of participants. Therefore, the implication for therapeutic citizenship is a corresponding impact on the economic front through these cultural, symbolic and social factors. Material issues that emerged in the dialogues appeared to be a way of HIV temporality and biomedicine demands shaped by contemporary aspects of capital theory (cf. Lin, 2017) that relates to development about transferability of HIV resources into another, for instance from the medical to psychosocial (Campbell et al., 2012).

Further, socio-economic changes following the medicalisation of HIV are not simply a product of living with a chronic health condition, but the outcome of particular stages in its development. This study found that HIV citizenship requires attention to tendencies that are transformed and reproduced by ART medicalisation (see also Flowers et al., 2012; Williams and Gabe, 2015). Consequently, the interrelations of health, development and therapeutic citizenship are multilevel. First, teachers are understood as actors with a large effect on development agency. Second, since normalisation is not smoothly achieved by medicalization, and is in any case itself of ambiguous value, it cannot be assumed that therapeutic citizenship will unproblematically promote development. Third, the lived experiences of HIV positive teachers reveal a social construction of working in schools ‘with’ HIV that is defined by wider communities and which underpins the extent of productivity that participants describe. Finally, therapeutic citizenship in development ought to be seen within the context of limits that biomedicine - and sociality - generate within it.

The current SDGs may not be achieved for most African nations, including Zambia, if health-related issues are not dealt with fully (WHO, 2016). Therefore, health is a means to development, and the implementation of the SDGs ought to focus on goal three – good health and well-being – in order to achieve goal one – no poverty. The combined

efforts to achieve the SDGs reduce the threat of communicable and infectious diseases - without necessarily mitigating the medical and non-medical challenges of living with chronic conditions like HIV that affect national development (D'Alessandro and Zulu, 2017). It is hard to eradicate poverty in any form without first addressing the health issues of a given population. For example, participants in this study were more concerned with the health condition of their bodies than with other basic life requirements, including having a job. However, once health is attained, participants put economic issues at higher level of priority. This prioritisation of needs signifies that until health matters are resolved at an individual or national level, eradicating poverty will be far from being feasible.

If health is a means of national development, then achieving the SDGs in Zambia will depend on the management of chronic conditions with key groups, such as teachers living with HIV. Additionally, more ART patients each year mean that the government should continue to increase resource allocations to HIV testing and treatment annually, which perhaps can strengthen therapeutic citizenship as well as advancing arguments for an increased budgetary allocation. High life expectancy among teachers now, in the treatment era – compared with the early 2000s, when HIV treatment was at its lowest and even inaccessible for most people – has altered the demography of the nation and created more skilled labour in schools.

Health is crucial to economic development but can be constrained when one has a lifelong illness (Marmot, 2015). When it comes to personal development, participants regularly expressed this constraint in the context of their economic advancement. Moreover, the lack of material support from the state heightened the negative development implications of therapeutic citizenship. The continued need to provide for basic needs, positions teachers in the context of health as a burden to themselves, their families and the state. Although there is high job security in the civil service, the need for state protection against standardised – and low - wages that do not take health conditions into consideration for extra incentives is overwhelming when one is living with HIV. ART provision by the government is a form of material dependence, and such demands for welfare resources from the state denote a sense of being different and largely passive when it comes to making claims beyond medical resources, as shown by Patterson (2015).

HIV and AIDS have a powerful micro and macroeconomic downside. One of the many prerequisites of national development is a vibrant public sector (Cosgrove and Curtis, 2018). The temporality nature of the HIV epidemic has reduced the ability and effectiveness of public service delivery, for instance of education but also of health, agriculture and even tourism. HIV and AIDS is major barrier to national development through a focus on the biomedical aspects of ART. The demand to keep citizens on treatment puts pressure both on already limited national budgets for health, and at the more personal level of health driven and constrained by the workings of ART, as can be noted in Njamba's statement (see chapter five), cited again here:

Njamba (Male, 37): I normally take my medicine around 21:00 hours. When I go for class in the morning, I feel dizzy. That affects the implementation of my lesson, especially if I have not eaten anything. When I get dizzy in the middle of my lesson, it affects me so much. [...]  
Because when I take the medicine, I need to make sure that I go to bed and sleep. After I take my medicine at 21:00 hours, I go to sleep, because after taking the medicine I cannot do some activities. It has limited me in terms of movement after 21:00 hours [... and conduct] responsibilities that require me to move around a lot and lose a lot of energy. Though teaching is not strenuous, there are co-curricular activities that are strenuous and can cause stress.

The disruption and (de)professionalisation of ART imply that teachers living with HIV cannot apply complex pedagogical approaches in their teaching. As can be noted in Njamba's words, ART's effects on the body can limit or even prohibit the use of labour-intensive teaching sessions, such as those using heavy teaching aids or physical demonstrations done in or outside the classroom. Class experiments and demonstrations that need careful preparation can also be hindered by the psychological and physiological side effects of ART. Not only does this restrict activities that might improve lessons, but also the topics that relate to HIV are hard to teach for some participants. Although useful for their continuity of work, and for much of their continuing and sometimes enhanced sense of professional and personal effectiveness in the world, ART at times diminishes the role of HIV positive teachers in national

development, which is differently situated. For instance, through reported temporal and periodic loss of memory when teaching which was associated to ART by participants (see Table 5.7).

Linked to the current study, there is a very subtle process which emerges from some participant responses, of HIV ‘underdeveloping’ public services. Therapeutic citizenship is not only related to complex treatment challenges, but puts into difficulties quality service delivery for the public in Zambia’s education system. The fluctuating side effects and the disruption of life by ART hinder the prospects of HIV positive teachers upgrading their qualifications for quality education delivery. Constraints created by life on ART and/or limited ability to access treatment were prevalent in rural areas due to the absence of healthcare services and the distance from the hospitals that HIV positive teachers needed. The lack of health services is a development issue that impedes the full utilisation of HIV positive teachers as a human resource for the common good in the long term.

The political agency and social stratification associated with ART are ambiguous; they can lead to socio-economic inclusion and/or exclusion. Based on the findings, the majority of participants remain underprivileged, even though they have a job, due to health-related issues that are essential for development. The ill health of citizens can become an obstacle to meeting sector targets, such as in education, especially in a low-income country such as Zambia where education targets are already difficult to meet. The difficulties of citizenship when living with HIV have direct implications through the nature of ART temporality for the epidemic in a low- or middle-income country, due to the long-term need for the ART supply chain. In this view, what is supposed to be a development state is transformed in the case of Zambia into a para-state (Whyte, 2015) due to the dynamics of outsourcing medical supplies and external dependence for managing a large HIV positive population in the country. The rise of pharmaceuticalisation among key groups in low-income countries is associated also with the widespread ageing of people with chronic health conditions; hence the move towards a treatment network of bodily, behavioural and social conditions in need of international pharmaceutical interventions, at huge cost, by the state for affected individuals or groups, as also highlighted by De-Graft (2010) and Johnson (2016).

Since therapeutic citizens depend on donor aid in Zambia's health sector, this enables conditions for socio-economic development in the global north while obstructing the principle of self-determination for Zambia's socio-economic development. This situation speaks to the globalising nature of being HIV-citizenized, and the resource precarity at the national level echoes the participants' representations of local hardships of life on ART. Hence, citizenship is characterised by biologism, which transcends political notions of relations and belonging in a given country, to include the precariousness of medical resources. This global element and the limits of the state in HIV governmentality were well known to participants, as reflected by Sitondo:

Sitondo (Male, 42): Because I am very much sure that [Zambian] government on its own cannot manage us, we need donor aid.

HIV positive teachers' positionality in the development equation is not antithetical to but compatible with citizens' employability whilst living a medicalised lifestyle. Nonetheless, when one is living with a chronic condition, poverty becomes an additional burden and determines the form of care that individuals receive. Without monetary resources, the governance of illness is hard, and it has some social implications which then affect people's health and their experiences and representations of well-being and overall productivity. This research has found that differing forms of social and economic resource connected to development are driven by political elements attached to a medical lifestyle change.

HIV biomedicine has some aspects of biosociality which is a crucial element of national development. Therapeutic citizenship requires socio-political and economic resources at various levels for the 'normalisation' of medicalised bodies. Within citizenships defined by ART, my findings suggest, the most common and remarkable usage of sociality is to stand in for the economic substructure, especially around food, transport, housing, and the rationing and collection of pills on someone's behalf.

## **7.5 Discussion: repurposing therapeutic citizenship**

Some of the categorisations devised in this research are about understanding therapeutic citizenship, which involves the 'biological conditions' that shape public life (Petryna, 2004) as well as individual and collective claims made on the basis of medical needs

(Nguyen, 2008). Unlike in Nguyen's work, the notion of the republic of therapy in this study is deconstructed and reconstructed to cover the compounded citizenship duties of self-care rather than rights. The understanding that being HIV positive is about activism as a therapeutic citizen neglects the dissonance and continuity of everyday conduct when one is living with permanently incurable but treatable diseases. Therapeutic citizenship in the contemporary Zambian HIV context can rather be seen in the light of a 'muddled' progression from medical to social and political forms of living that include traditional as well as Western ways of managing health and illness by individuals within a collective biological-shaped identity. A new and revised identity is created by individuals who are on ART for various reasons, but importantly to adapt to the regimens and adjust to external influences (social bonds, clinic requirements, housing provision, nutrition, professional life as well as workload). Hence, some participants projected themselves as being healthy and happy individuals, while others considered themselves ill – although not to a level of physiological incapacitation – due to HIV and other mixed causes. The factors that shape life on ART are not an explicit focus of most work on therapeutic citizenship, something this research has added.

When people are on ART, their identity is changed to match their strategies for coping with being medicalised. Chronic conditions make people a lot less future-oriented (Larsen, 2016) – hence the significant contradictions between how people are doing socially and even personally, and how they represent themselves with HIV temporality (Yasin et al., 2012). The relation of those representations to social and personal realities is vital in therapeutic citizenship - founded on *ubuntu* which creates a threefold expression of citizenship: biological, social and political. Hence, the literature shows that the relationship between private and public, active and passive forms of citizenship in *ubuntu* is distinguished on clusters of national identity within mainstream social structures of living in SSA (Ratele, 2016; Tarkang et al., 2018).

However, therapeutic citizenship status raises limits for *ubuntu*, which rejects the individual as the site of problems, instead prioritising the mutual ownership of the community. Since the disclosure of an HIV status is primary in acquiring this form of citizenship, disclosure is part of *ubuntu*, but it is less required for *ubuntu*. Nguyen's (2008, 2010) work may appear dismissive in terms of how people use testimonies to access treatment, because in his study the 'muddling' of HIV treatment for participants

is not explicitly explored, and the implications of living with HIV after disclosure techniques are used to access treatment can be too collectivising, so that diverse individual accounts of ART experiences (see chapter five, Table 5.7) may be untold and neglected. *Ubuntu* based on disclosure can perhaps deny what is essential in people's health, as disclosure of HIV status is not needed to feel a sense of belonging and inclusion in collective actions. Additionally, where people have disclosed, there is a possibility of faction formation within their communities when dealing with problems, including illness. *Ubuntu* traditions can lead to silence when it comes to HIV, and this can lead to rumour and the development of stigma. On the other hand, *ubuntu* points to the sense of collectivity within communities, which can serve to reduce HIV stigma and also gender differences in relation to HIV. This finding relates to the factors that make up ART-competent communities, as argued by Campbell et al. (2012), which include knowledge, dialogue spaces, owning the problem of HIV biomedicine locally, projecting collective action benefits, resource mobilisation, networking, and partnerships of communities and agencies at various levels.

In spite of the above limits, *ubuntu* traditions in managing illness are advantageous because of their emphasis on collective living through which individuals are helped to be productive citizens by and for others. In the case of HIV, manifestations of *ubuntu* can, though, suppress differences, and can neglect elements of disempowerment that are associated with pharmaceuticalisation and the medicalisation of bodies. In this regard, this research suggests a redefined form of *ubuntu* which is based on community changes for those living with HIV, and the formation of alliances with community members who are not HIV positive but who are what we might call 'affected allies'.

This study posits that individual HIV situations for citizens are central in the effort to attain SDGs or national development. However, elements of neoliberal management – even new public management – are increasing the commercialisation of HIV, which has a negative influence on health social policies for low-income countries (Fine, 2017). Thus, when it comes to the economics of ART provision in Zambia, the supply of HIV drugs is unclearly divided between domestic and external funding, especially among participants and in studies such as that of Siameja (2011). Low-income countries appear not to provide as much of their budgets as middle-income ones. How much the Zambian government is putting into the procurement of ART is often overshadowed for

participants by donor supplies of ART. The scenario with this for the future is that perhaps Zambia will have much bigger issues with inadequate external provision, as elsewhere in Africa. For example, Uganda's HIV programmes faced aid suspensions and funding cuts owing to the anti-gay laws (Butagira et al., 2014). These events in other countries are evidence that highlights a real risk of depending on donor aid for medical resources in the governance of long-term chronic conditions, such as heart conditions, pulmonary conditions, diabetes, and blood pressure.

Although Zambia has not been prevented from making its own provision, over-reliance on humanitarian aid for the lifelong chronic conditions of citizens may disempower post-colonial African states, their industries and economies in the long term, which may be similar to the effects of structural adjustment. With the above framework and projection in mind, Zambia is absolutely a client state of pharmaceutical corporations, as more and more citizens, such as teachers who have limited resources and are HIV positive, rely on free access to ART (Ecks, 2005; Johnson, 2016; Persson, 2016).

The above attributes have a secure connection to HIV biomedicine and framings of citizenship, including those emerging in this thesis. Therapeutic citizenship describes duties of the state, but when appropriated through *ubuntu*, it includes ideas about respecting other citizens and showing empathy to all to promote for communal cohesion. Within *ubuntu*, the people living with chronic illnesses enjoy entitlements without any corresponding obligations as 'private' citizens.

This next passage shows the 'repurposing' of therapeutic citizenship for development. Disclosure requirements for privileges and HIV treatment are positively contributing, through the longevity of skilled and experienced human resources such as teachers living with HIV, towards national development efforts, particularly when it comes to meeting educational goals in Zambia. However, the costs of managing a pandemic are a part of the therapeutic citizenship spectrum that often has implications for national development in other sectors. The Zambian government's and its cooperating partners' commitment to halting the effects of HIV is evident in the increased budget allocation for ARVs, for example, from US\$4 million in 2011 to US\$44 million in 2016 (MoH, 2016). Such huge funding directed towards treatment, care and prevention programmes possibly diverts resources from other vital sectors to support HIV/AIDS programmes.

Donor resources and civil society resources, as well as government resources, are also HIV-skewed. From the data emerging in this study, participants have a strong awareness of donor dependency and what that does both to their lives and to the country, and that this is part of being a ‘therapeutic citizen’.

It is possible, that with the gradual introduction of ART and the decline in HIV-related deaths in the education sector starting in the late 2000s (Munachaka, 2006), many Zambian teachers – both those who had lost their spouses and those who were recently diagnosed – sought treatment early in what several participants termed the rush for ‘lifesavers’. For example, Miyanda remarked:

Miyanda (Female, 43): ARVs are my life because if I do not take this medication my life will be shortened... my medicine is life.

The above suggests as we have seen before that HIV as an illness makes medicine the focus of life itself, and anything that happens beyond the medication is – in times of illness especially - relatively insignificant. Citizens who get tested for HIV and put on ART carry with them a recognition that they are reliant on medicine for their very survival, and that this is heavily reliant upon external donor support, which can be described as a form of coloniality around ART.

In general, therefore, it seems that the rise of HIV medicalisation in schools is transforming their nature as epicentres of social interaction. Of particular significance is the fact that teachers mostly discuss their health challenges or statuses not in school, but rather at the clinic when they meet at random during the refilling of medicines. They therefore can usually only be therapeutic citizens outside of their precariously middle-class employment role. Again, these variabilities across class and other social contexts have not been considered within considerations of therapeutic citizenship so far in the existing literature.

## **7.6 Chapter summary**

This chapter has discussed how being HIV positive and on ART makes one acquire and develop therapeutic citizenship status in a country such as Zambia. Manifestations of such citizenship are diverse and shaped by people’s gender, age and professional life;

they also serve as a socio-political basis for establishing medically founded values and forms of sociality. The chapter went on to suggest that medicine creates a culture of biopolitics that enables participants to engage in biosocial practices mediated by medical interventions. These practices may indirectly or directly stifle efforts to meet national development goals across sectors.

Thus far, the thesis has argued that therapeutic citizenship in general, and for specific groups such as Zambian teachers, is framed by global and national politics, policy and media. HIV Biomedicine and social relations ranging from the interpersonal to those of civil society (Whyte, 2012), all position HIV temporality not as a potential emergency, as in Nguyen's (2010) research, but as a chronic, pre-eminently medical and largely solved problem, with positive contributions from individuals who are on ART towards communal well-being, as explained above, in the Zambia context, through *ubuntu* traditions.

This chapter has also demonstrated the centrality of elements of decoloniality in a therapeutic citizenship context. It has been shown that ART provisions are moving towards an intersection of medical and social knowledge production and intervention for people living with HIV in the long-term for the quality of life. Hence, the temporality of HIV is creating a new politics of living with HIV, which continues to change lived wisdom about ART daily living, knowledge about which is used for this daily living.

In the next and final chapter, general propositions about therapeutic citizenship derived from the research, core findings that relate to the research questions, study limitations, and some personal reflections on this research are discussed. The study's contributions are highlighted, and issues that were not part of this research objectives but were prominent in the findings are also suggested for further investigation.

## **Chapter eight**

### **Conclusion: final thoughts, thesis contribution and future research**

#### **8.0 Introduction**

This research has examined the nature and processes of therapeutic citizenship status acquired by HIV positive schoolteachers who are on ART, and further has ascertained this status's implications for Zambia's national development prospects. Teachers, who are a key group for those prospects, are also disproportionately affected by HIV. The thesis involved semi-structured interviews with a sample of 41 HIV positive teachers in two different Zambian regions, and drew from fieldwork interviews. The theoretical frames of identity, chronicity and governmentality were initially explored and used in this research as lenses through which therapeutic citizenship could be understood and appropriated.

This is the final conclusion chapter, which has six sections. First, an overview of the conceptual and methodological approaches as they developed in the thesis is briefly given. Second, I address the three main research questions and how the thesis has answered them. This section extends the discussion by highlighting practical and theoretical insights about citizenship in the HIV context. Third, a reflective account is given of fieldwork experiences and this research in general. Fourth, study limitations are addressed in the order that moves from more specific to the more general theoretical ones. Fifth, I make suggestions on topics that need further investigation. The sixth section gives the key contributions of this thesis are explicitly discussed, as generated from the findings and analyses in the research. A brief closing section provides some final thoughts on the research topic broadly, warning against generalisation, and against treating HIV as an eradicated illness crisis due to ART's medicalisation of it, across different settings and for various professions.

#### **8.1 Overview of conceptual and methodological approaches**

Assessing the level of a population's health cannot be satisfactorily done without qualitatively considering the economic, political, social and psychological effects of living with a disease that requires daily medication (Wahlberg and Rose, 2015:61). This research involved a review of theories, which then led me towards examining the

core questions of the study through qualitative investigation and analysis that addressed the material through three thematic levels of increasing complexity.

As I endeavoured to show in chapter three, the use of concepts of governmentality, identity and chronicity can help us understand the dynamics of HIV health and illness. ART has rendered HIV first as a chronic illness that was a human tragedy but is now treatable, and second as having long- and short-term effects on the socio-economic, physical and psychological health of those diagnosed with and affected by this disease (Lichtenstein, 2015:858). The emphasis here is on the second stream, with the first stream a kind of memory that needs consideration and that is often 'disappeared'. The two streams are thus unequal, because the first stream is now much weaker due to advancements in treatment technologies, yet neglected.

When critically synthesised in relation to these streams and their meanings for HIV therapeutic citizenship – i.e. subjects' relations to the socio-historical particulars of medicalisations and normalisations of HIV (Nguyen, 2008; Patterson, 2015) – the above concepts of governmentality, identity and chronicity offer new ways of understanding medical solutions, normalcy and their limits in the everyday lives of teachers in Zambia who are on ART. This synthesis led me, through an initial thematic analysis of the interviews, to cluster findings into categories that related to medical, social, economic, professional, political and cultural factors, as discussed in chapter five. The synthesis also led me in chapter six to reframe the concepts I had started from in relation, instead, to biosociality, temporality and medicalisation.

Through a second-level thematic approach that brought the findings and theoretical framework together, chapter six demonstrated that there is a symbiotic relationship that exists between the biological, social and medical. That is why discourses of HIV chronicity and its substantive realities are tied to life histories of participants through a process of becoming, which points to the temporal possibilities and challenges of living on ART. HIV medicalisation is intrinsic to decisions made based on diagnostic categories of living on ART in the long term, which lead to formal and informal network structures of HIV biosociality, connecting affected individuals and forming groups mainly on the basis of identifying with daily ART governance.

Chapter seven, arising from a third, higher-level thematic analysis of some of the work in chapter five and the themes in chapter six, highlighted the problems and prospects for a stratified form of therapeutic citizenship and its implications for not only development but also indigenous practices in medicine through elements of decolonial theory, especially on ART in Zambia.

The manifestation of HIV therapeutic citizenship has always been distinctive, because it exemplifies privilege as well as disadvantage and ongoing uncertainty. This thesis showed in chapter five that HIV-citizenized individuals in the contemporary ART era enjoy certain rights and overcome uncertainty based on three factors: medical, psychosocial and material. Hence, therapeutic citizenship remains a socially imagined form of group particularity within a wider nation-state, limiting the biomedical ‘success story’ of ART’s ability to normalise everyday experiences of life on ART to the extent that people with HIV can be viewed as citizens ‘like everyone else’. In addition, seeking teacher agency in communities, for those on ART in Zambia and elsewhere, counter-intuitively bears the risk of covering over the challenges faced when one is living with HIV, by treating citizenly agency as undifferentiated by HIV. Treating everyone as biological citizens denies groups of HIV-citizenized individuals the privileges of otherness as well as of an HIV collective identity.

An acknowledgement of the specific and context-based nature of the thesis’s findings around contemporary therapeutic citizenship still permits me to suggest a level of generality for some arguments made in this thesis. In Zambia as in other national contexts, ART has led many people to recover from HIV-related physical health deterioration, and, as, perhaps, in other countries, has also enhanced the state-citizen contract due to the free distribution of ART. HIV identities have both positive and negative effects on teachers’ citizenly, social and professional value in this research, and these findings may have relevance for teachers and other professionals particularly within high-prevalence epidemics. Although in chapter six the study suggested that the medicalised governmentality of ART shapes HIV identities, it is consistent to say that locality and cultural practices in a community also determine how people experience and govern life on ART. Based on chapter seven, *ubuntu* can be used to understand the effects of social and cultural aspects on different forms of health and illness representations. The use of local initiatives in the results is part of *ubuntu* which has

relevance in other situations. For instance, rites of passage require knowledge (re)production as well as preservation of indigenous practices generated and passed on from one generation to another, in some indigenous African communities, through *ubuntu* (Turner et al., 2017).

In the next section, I address more systematically the research questions raised at the beginning of the thesis, and the thesis's answers to them.

## **8.2 Findings' relationship to research questions**

This research sought to address three main questions, and objectives, which shaped the direction of the thesis. Here, I address the questions and objectives shown in chapter one by collapsing them into conceptual framings and relating them to specific chapters, at times associating them with findings in chapters five, six and seven.

In chapter five, it was demonstrated that the effects of HIV are about not just how individuals govern being on ART but also the role of others around them in the process of medicalisation. The relationality of ART temporality reported in chapter six shows elements of political, socio-economic, resource-precarity and gender-based inequalities in HIV. Participants' views on their understandings of ART's workings are majorly affected by the medical systems which partly normalise life, against the psychosocial aspects of HIV medicalisation discussed in chapter seven. In the section below, I demonstrate what the findings (across chapters five, six and seven) say about therapeutic citizenship in HIV biomedicine, sociality and temporality as reformulated moves from the key concepts of identity, governmentality and chronicity, as well as *ubuntu*, as a partial response to the complexity of HIV medicalisation.

### *8.2.1 Participants' comprehension and management of health and ART medicalisation*

How HIV is understood is also, the thesis's findings suggest, highly gendered. The results show glaring differences in knowledge and coping strategies between male and female participants. For example, in chapter five, it was noted that ART was mainly reported as working for women, whereas for men it was restricting. The repetition of HIV difficulties in responses was more common among men. Hence, ART chronicity was presented in a positive way by more women than men, as reflected in chapter five.

Female teachers (long-term survivors) with early diagnoses had somehow managed to adapt to ART faster than their male counterparts. But overall, a high number of participants, regardless of their period of being on ART, talked about the difficulties of getting fully acquainted with the workings of their ART chronicity. Moreover, in chapter five, the ways in which participants comprehended their health condition was shaped by their experiences of sickness and the state of relations or support for meeting treatment needs in the long term, especially when ageing with HIV. In chapter six, the effectiveness of ART was related to temporality because of the difficulties encountered in the assimilation process of what was presented as the ‘ritualised’ nature of HIV treatment by the majority of participants.

Generational differences played a role in HIV chronicity and temporality, and in how identities and socialities were produced. The longer they had lived on ART, the more participants had integrated other parts of their lives into a medicalised lifestyle, while also being able to differentiate the parts of their lives that were not related to HIV – identity and sociality were not defined only by the condition. As a common finding, participants who said HIV did not define them did not belong to the earlier generations – independently of their time on ART – who had been part of the AIDS ‘crisis’, as described in Barnett and Blaikie (1992). But as discussed in chapter five, HIV is no longer a crisis in Zambia, and the ‘HIV does not define me’ narrative had less emphasis than it might have done earlier in the pandemic. Therefore, to some extent in Zambia and elsewhere in Africa, HIV citizenship becomes a larger thing that assumes a defining role in ‘non-HIV’ aspects of people’s lives but does not reduce them to it – something that this research has added, since other studies, such as Whyte (2014) and Bernays et al. (2016), seem narrow as they do not focus on HIV research elements’ related factors that this research has taken forward.

In chapter six, it was noted that contemporary experiences of ART shape perceptions of health and illness. The sociality that appeared around HIV in participants’ representations sheds light on the medico-social phenomenon of HIV as being embedded in a variety of short-term and long-term experiences that are both socially and medically driven. An HIV positive teacher goes through a process of altering their thinking, emotions and behaviour. This constructs an identity that is not fixed by ART –

although it may be at the start – and that also varies depending on personal circumstances. As the analytic move in chapter six from chronicity to temporality indicates, living with HIV is a changing process that brings new realities across time. That is why the concealing and revealing of the ‘HIV self’ can be understood as medically and socially situational.

It is also through relationships that necessary information about HIV is shared and ART coping strategies learned and developed. Peer support groups and family or colleagues at work can be a source of ART adherence. However, the presence of stigma in the ART era is twofold: it affects both private and public domains of coping with HIV. Participants were attached to their sense of self when their family and networks of friends were accepting of their HIV status. Similarly, in chapter six, it was contended that HIV socialities’ self-acceptance and disclosure techniques were fundamental for identifying with individuals and group inclusion. Also, interaction with health personnel either promoted ART adherence or increased stigma, which was reported to start from hospital. The sense of self-description for most participants, in chapter five, was foregrounded and was primarily based on thinking about their professional selves before considering anything else, such as their HIV positive status.

The lack of adequate information and counselling services appeared to have increased mental health issues among participants. Presently ART-related mental health problems often go untreated, as they fall outside diagnostic categories that can be medically detected. The absence of psychosocial services that go beyond diagnostic forms of HIV management seems to be associated with undetected and untreated mental illnesses related to ART in Zambia. As was discussed in chapter six, there is a greater concentration on HIV biomedicated bodies than on mental issues of ART temporality.

The lack of medical care for HIV mental health issues connects with the informational resource issues shown in chapter six, Figure 6.1. In participants’ transcripts, normalcy was represented through improved physical aspects and not mental health. The focus on the body demonstrated either little or no adequate information and awareness about remedying some of the likely adverse psychosocial effects of life on ART.

Although teachers are expected to be resourceful, the impression from the thesis findings is that over 50% of the participants had limited means or desires to access valuable HIV information. Their complex interactions with people, medical demands and material needs were at the centre of how participants either comprehended or coped with their HIV chronicity. The low quality of and non-access to both HIV- and non-HIV-related resources made self-governance techniques different based on age, locality, gender and teaching (qualification) income scale. Hence, chapter six points to a shift from the governmentality of the subject to a more differentiated biomedical practice that even touches on the notions of *ubuntu* discussed in chapter seven.

The move from governmentality to medicalisation is underpinned by participants' opinions on the transformation of forms of stigma and a sole reliance on medical interventions for a healthy life. The coping strategies reported in chapter five indicate a transition of governance from a non-medical to a pharmaceuticalised lifestyle in HIV self-care and state help priorities on medical resources for specific groups. In chapter five, the findings on teachers and HIV may reflect or differ from findings on other professionals and other civil servants in Zambia, because those studies are earlier as can be seen in Bond (2010). They may also differ from findings in other high HIV prevalence countries such as South Africa, as found by Endicott (2019), Cullinan and Thom (2009) and Fassin (2007).

The job of teaching when on ART offered a means of living and sources of knowledge for these teachers. However, it was reportedly hard to be HIV positive in this profession due to teaching load stress in the context of chronic illness, treatment difficulties, stigma and secrecy, and distant clinic appointments, although it was fulfilling when learners achieved. It was from the ability to teach and work that most participants developed a consciousness of still being contributors to communities as HIV positive citizens, and a valuable sense of an HIV positive social and profession self, which led to the move from identity to sociality. As the thesis showed in both chapter five and chapter six, this self-identity is always socially situated, and indeed has in many cases a specifically African communalised character that relates to the concept of *ubuntu* discussed in chapter seven.

Nonetheless, this research has shown that the management of a chronic health condition such as HIV includes technologies of the self, acting as powerful versions of governmentality, with a specific framing, as chapter six demonstrates, around medicalisation, similar to findings by Flowers (2010). However, in the African context, *ubuntu* seems to refuse a singular subject, as it emphasises local communities and kinship groups in dealing with illnesses and other life challenges. Medicalised governmentality in the context of *ubuntu* has its own specific characteristics: it is collective; it emphasises interactions; it assumes commonality. With the above in mind, and as many Zambian citizens, including important population groups such as teachers, get ‘medicalised’ through ART, there are wider long-term challenges and possibilities around material and medical resources and their sustainability arising from the possibility of taking an approach to HIV citizenship founded in *ubuntu*.

In chapter six, this study described how patterns of medicalisation increase decision making power for health personnel over participants as clients. This power issue can also be related to participants’ high vulnerability to biomedicine and temporality uncertainty, especially in the absence of adequate knowledge about ART’s workings and continuing stigmatisation, which persists to some degree independently of levels of HIV knowledge and experience. That is why participants kept repeating narrations of hardships and uncertainty because living a medicalised life is not linear but entwined with unpredictable social and medical encounters that can be either empowering or disempowering.

To the extent that being diagnosed HIV positive changes perceptions about the illness, through ART – which is now encountered almost concurrently with diagnosis – it also redirects beliefs about health over a protracted period. Being HIV positive still describes for majority of my participants having a ‘spoiled’ life identity, followed or paralleled by the opportunity to live better through ART. The mobile notion of temporality discussed in chapter six again exemplifies this point, as it explains the changing and variable mental as well as physical effects of ART, rather than a single chronological progression within HIV socialities – a finding that is not prominent in previous studies such as Horter et al. (2017).

Additionally, the subjectivities of HIV citizenship involve construction of the self within social and individual experiences. Thus, in chapter six, biomedical HIV experiences were described as useful in developing a sense of belonging and an associative progression of events (from diagnosis to treatment). The use of ‘we’ and ‘us’ by participants, as given in chapter five, represents an HIV subjectivity that is collectivising; even though ART adherence requires individual responsibility that finds meaning through HIV socialities, as also shown by Whyte (2015).

It is the contradictions and perhaps counter-intuitiveness of some participant representations that point to the difficulties of a shift in behaviour to align with an HIV self or social identity for participants, as depicted in chapter six. This thesis demonstrated that a disconnected, fragmented self is represented in participant accounts that offer medically linear and socially parallel – and by this token, somewhat separated – representations. The representations analysed in chapter five, on positive positionings of the HIV self, are considerably intertwined with the values of teaching, as opposed to the hardships of managing life on ART. They link those positive positionings to continuing professional life, and even at times to aspects of professional success that draw on or address HIV. Based on the above, and as shown in chapter seven, therapeutic citizenship is complex in the way aspects of biomedicine counteract with socialities of HIV temporality.

Finally, complex and often opposed perceptions of the successes yet limitations, the liveability yet difficulties of HIV in the ART era were common in participants’ accounts. Although HIV seems to be a resolved issue through ART’s success, and HIV to be a small part of many HIV positive people’s lives, there are several challenges presented by it, as discussed in chapter five: taking pills every day and long term is hard for some participants, and forgetting about it as well as being conscious of it makes life complex. *Ubuntu* is a kind of partial response that situates this medical and social complexity of living on ART in participatory care of others in a community, as discussed in chapter seven. This way of considering *ubuntu* in HIV research is unique and goes further than Tarkang et al. (2018), who looked at *ubuntu* in terms of sexual behaviours and stigma.

In the section below, and based on the findings, I briefly show some of the social and professional elements that made living with HIV biomedicine and ART temporality complex for participants.

### *8.2.2 The social and professional complexity of living with HIV for participants*

Many interrelated issues make living with HIV a complex and problematic endeavour for a teacher. The difficulties and possibilities of living a healthy life for an HIV positive teacher were partly due to the complexities of medicalisation and its social contexts, as explored above. However, these difficulties were a consequence of non-medicalised aspects too. Location is one key factor. Locality tends to shape the quality of interactions and the lives of participants.

As noted in chapter five, access to quality and effective HIV care can be hindered by distance and the unavailability of resources in some areas. It has also been mentioned that teachers' role and status concerns specifically lead them to often use facilities a long way away, requiring transport. Hence, HIV complexities for participants connect with not only economic but also transport. The relation of this socio-economic complexity to therapeutic citizenship, in chapter seven, is that being a professional limited the support that some participants received in a given community, due to their middle – class status, at least in the Zambian context of being teachers.

Additionally, the achievement-oriented assessment of teachers' work adds extra pressure on their health condition. ART hardships, for instance around side effects and the need for food, are heightened through the precarious socio-economic condition of having employment yet a low income and at the same time being responsible for others' welfare – pupils and family. In chapters five and seven, it was discussed that the lack of resources also puts a mental strain on individuals living with HIV who must provide for their families while they also take care of their own long-term medical requirements. It is within this dual recognition and individual responsibility that therapeutic citizenship requires active manifestations of HIV social and medical identities of the self, which can also be used as a basis for receiving help (see chapter five) and that have emancipatory importance.

There are difficulties for some in feeling fulfilled and ‘normal’ at work. The work is difficult, especially in the under-recognised context of their chronic illness; yet they also feel pride in what their students are achieving, making their HIV less relevant and less stigmatising to them, as evidenced in chapter five. However, the complexity of life on ART also lies in the transformed forms of stigma that now focus on treatment markers and not physical bodily frailty, as also discussed in chapter six.

From participants’ accounts, there are difficulties for them regarding HIV positive learners interacting with their own condition. The physical spaces where participants find themselves, such as school and hospital, powerfully shape identity. When teachers who are HIV positive meet learners who are also on ART, it complicates the sense of their being caregivers to learners with a condition for which they too need support. Other elements make the school an explicitly hostile environment for disclosure – for instance, through strong positions on ‘conceal and reveal’ by participants, which were dominant in some findings shown in chapter five. Given the above, HIV governance is ‘disabling’ of specific actions of teachers. Therefore, the enabling aspects of therapeutic citizenship mentioned in the prior sections emanate from medicalised status more than from these social situations.

As shown in chapter six, participants cared more about their biological citizenship in the form of access to ART than about an active public life, which suggests a passivity of living with HIV within wider national, social and political systems. However, from findings in chapter five, disclosure – such as when participants meet at the hospital with colleagues who they never knew were on ART, and also when there is some negative talk or gossip by colleagues about HIV-related topics as well as fear to take HIV pills in public – can complicate and even create social divisions in the workplace for teachers, thereby showing that HIV temporality is socially denormalising through the medico-social disruptions it generates in people’s lives.

Participants’ self-descriptions, going beyond being a person who is living with ART to being an HIV positive teacher, demonstrated the essentiality of professional roles. For a self and identity that moves beyond individual images to involve HIV socialities (discussed in chapter six) – can transcend a chronic and stigmatised health condition of therapeutic citizenship, which has effects on national prosperity. This connection

between the individual sense of selfhood and HIV sociality in chapter six led to the next section, which reflects on how chapter seven examined the implications of therapeutic citizenship as a mode of medicating bodies and normalising chronic living for key professions and groups such as teachers living on ART in Zambia.

### *8.2.3 Implications of therapeutic citizenship status for national development in Zambia*

Therapeutic citizenship was reformulated in chapter six to mean a biomedically led form of living that shapes socialities and patterns of temporality beyond medicalisation networks and the service of state control. The citizenship context and engagement may depart from the traditional meaning of the concept, because of the involvement of HIV socialities that are not only medically formed but biologically driven in non-medical settings within a given period. The level of public participation in this type of citizenship seems to be mainly passive, but only outside one's professional life. Nonetheless, *ubuntu* traditions which are about the relationality of life on ART, discussed in chapter seven, make therapeutic citizens active to some extent in their everyday lives, making therapeutic citizenship in that case also collective, which is less centrally the case in the traditional and even later formulations of the concept shown by Patterson (2015) and Rhodes and Paparini (2016).

Since people on ART but still ill and unhealthy expect the state to provide monetary support in form of disability allowance in countries such as South Africa, HIV citizenship can also establish an active citizenry which uses its health condition to make claims on social welfare schemes, as found by Bullied (2016). In the case of Zambia, medical resource provision makes citizens not very active in demanding other entitlements, because of their teaching salary, a consciousness that the state is doing enough by providing free ART, and limited civic education about the state-citizen contract regarding the welfare obligations of the government and the entitlements of being a citizen of a given jurisdiction, as articulated in chapter seven.

Since ART improves physical well-being, and as individuals stay in their teaching jobs, they can help themselves to some extent through their salaries, and contribute towards national development through taxes and by training the pupils that are the country's future human resources.

Chapter seven established that any understanding of therapeutic citizenship needs to pay attention to discourse, which involves structures of language and power. Hence, ART practices were not separated by participants from their discourses of being an HIV citizen. The human resource enhancement brought about through therapeutic citizenship in the generation of healthy, active working HIV positive subjects who are framed as Zambian as well as pharmacological citizens happens not only through HIV positive teachers, but through other professions in different sectors and forms of chronic health condition that require medication. It is therefore beneficial in other productive sectors such as agriculture, tourism, mining, medicine and construction as well as education.

The functional health (as distinguished in chapter two) which HIV positive teachers enjoy means that more and more experienced teachers are retained and continue to serve in their positions until retirement age, as ART increases their life expectancy. Others use their acquired knowledge about the process of living on ART to share information about HIV and health. But the extended benefits nationally of prolonged life for teachers who are living with HIV are countered to some extent by the large demands on government resources.

In addition, given the difficulties reported in this study around memory loss, resource constraints, and poor or fluctuating health, teachers may not meet the demand to produce well-educated learners – an issue that HIV and education research, such as Kelly (2000) and Kharsany et al. (2016), do not account for. ART experiences can negatively impact pedagogy, thus diminishing, at least among HIV positive teachers, the important role of education in national development. The compromised quality is perhaps also partly due to, beyond poor health which is more important than, limited training opportunities, which are constrained by participants' and government's focus on the ART adherence and governmentality (which chapter six reframes as medicalisation) of a body that moreover lacks other HIV-relevant resources such as food, transport or housing, since (as also found by Kim et al., 2017) teacher salaries are inadequate, as evidenced in chapter five as well as chapter six on informational resources and uncertainty.

There are some effects that participants' HIV may have for other teachers, such as having to take up lessons when there is a hospital appointment, which would mean more workload. Also, non-participation in teaching evening classes for extra income due to the schedule of taking ART drugs may put pressure on other teachers who are HIV negative, as indicated in chapter five.

From the above, it can be suggested that the implications of therapeutic citizenship status for HIV teachers in Zambia are that teachers' health, particularly HIV-related health, is an important, though compromised route to development, although not the only or sufficient route to development. As seen earlier, no meaningful national development can occur without paying attention to crucial groups' health issues. The resource burden involved in such attention, alongside the limited skilled labour force, can affect national development. Yet when citizens are healthy on ART, they are able to be productive in their areas of work, and money that might otherwise be spent on dealing with ongoing and serious medical problems resulting from untreated HIV can be channelled to (and utilised on) other projects, thereby enhancing national prosperity.

The reformulation (in chapter six) of chronicity to temporality (managing the present and mapping the future) that HIV positive teachers faced seems to be hard than HIV socialities to cope with, with less medical information around HIV issues other than ART, and few non-medical HIV support facilities within and beyond the teaching profession, as evidenced in chapter five. ART compromises the place of the teacher living with HIV in development, as the focus must be on self-care; yet teaching requires care's extension to learners. Sometimes, given the lack of support for and collective mobilisation around self-care, the two come into conflict. It is this lack of adequate support systems from the state, in education and for HIV-citizenized individuals, that is leading to the rise of a para-state as opposed to a 'developmental state' in the governance and pharmaceuticalisation of chronic health conditions such as HIV, as addressed in chapter seven.

### **8.3 Studying HIV positive teachers: my reflections**

Researching HIV-citizenized persons was instructive and informative, for both the researcher and the research participants, as discussed below. Embarking on a project to study HIV positive teachers was a daunting but possible task. Since teachers'

experiences of illness and health conditions have disruptive as well as positive effects, how HIV was represented was situational and based partly on the social and cultural background of participants. The populations sampled for this study gave accounts of their own lives and perceived experiences in relation to others, first as people living with HIV, and then as teachers. Most interviewees in this study were concerned about what was going to be discussed in the interview, especially as the majority had not declared publicly that they were HIV positive.

Undoubtedly, asking questions and letting the participants talk about their HIV condition was of crucial importance in this research. However, this was only possible after I had developed relations of trust with participants and had earned their confidence. Many of those who said they felt relieved after the interview noted that they had never had an opportunity to talk about their status in that manner with someone outside the family and clinic. Therefore, the process described in the method chapter, for conducting the interview proved therapeutic for some participants.

It was not a requirement in the interview for one to declare one's status. In general, the process of talking to someone about an issue that is considered taboo, both socially and culturally, appeared empowering, liberating and informative, and allowed personal reflections for interviewees such as Muna, who sent me a text which read:

Muna (Male, 42): The interview I had yesterday was very interesting, good and mind-opening. It really got me thinking about my status. Would it be good for me to publicly disclose my status to others? What do you think?

The extract above shows the beneficial and therapeutic nature of the interview process. But it also indicates latent vulnerabilities and power relations that proved a challenge for me as a researcher, in terms of positionality and reflexivity. It was difficult for me to respond to such questions from participants, other than making referrals to some associations that could give some help.

Researching a topic on a condition which is often kept secret was full of uncertainties in the recruitment process. Many participants remained undecided about disclosing their status beyond their inner circles. However, several participants agreed to be recontacted

for future studies, and wished that more people who were HIV positive were talked to in the same manner, as it had helped them reflect on their condition in a good way. This plea made by participants denotes continued experiences of stigma in the treatment era, which can be associated with a failure by the media to reverse the negative picture of the fatal legacies of a treatable condition.

Interviewing HIV positive people was the most overwhelming research project that I have been involved in during my career. There were moments when informants wanted solutions from me, while I had to conceal my emotions and let them play out when alone. Listening to stories about, for instance, husbands not disclosing their positive HIV status to their wives, or the gender-based violence and relationship disruptions that being positive had caused for several participants, was both frustrating and upsetting. Moreover, women's stories of being blamed for HIV infection in the home both moved and provoked a certain sense of anger in me as a researcher, but also indexed the vulnerabilities faced by HIV positive women, for whom my sympathies were further enhanced. In the end, what I thought would be an interview that captured more successes than difficult experiences of being positive and on ART was punctuated mainly by wistful narratives. Stories about death due to the potential withdrawal of treatment, lack of courage to test until one is bedridden – and even then, the continued refusal to take medication on one's sickbed – were disturbing to hear. I was worried to learn that people were not committed to taking available means of treatment, and that in spite of significant technological advancements many people with HIV were still ignorant of ART.

Emotions from participants were often visible. About seven interviewees cried, and interviews were paused for a break. There were moments when I would want to learn more about an issue brought up by a participant but then the interviewee would burst into tears and say they did not want to talk further about it because it reminded them of the pain they had been through. During those times I moved on to the next issue, which was slightly difficult as the participants were still hindered by flashbacks and their attention to the follow-up subject was diluted, even though they showed a willingness to continue with the interview. I addressed the aftermath of the interviews for participants who were clearly upset by providing some aftercare aspects such as words of

encouragement and also giving them options of joining support groups or organisations that I knew would provide care or counselling services.

Additionally, my personal and sensitive connection to the topic was difficult although not impossible to govern. Having family members who are HIV positive and on ART made me realise the psychosocial difficulties they have to go through in order to remain sane, even though their bodies look healthy.

I acquired information that helped me understand the need for and hindrances to good health-related practices. The fieldwork also enabled me to establish social and professional networks. The next section gives some of the notable study limitations.

#### **8.4 Study limitations**

The process of conducting this study was not devoid of challenges. These ranged from difficult fieldwork encounters and possible mishaps in the selected approaches to the writing and analysis of this thesis. Here I provide a reflection that accounts for this study's limitations. These limitations neither compromised the quality nor influenced the quantity of the data collected or how it was presented and analysed. Also, this study has revealed conceptual voids which it fails to address due to the limited scope in terms of theoretical frameworks and development, in HIV research in Zambia.

At the start of this study, it was anticipated that recruiting HIV positive teachers was going to be hard. With plan B on recruitment of HIV negative or unknown-status teachers in place, this anticipated limitation was not experienced, as enough participants were recruited (see chapter four). However, the backgrounding of other aspects of people's lives involved in any HIV-focused research – even when, as in this case, people do not have much opportunity to talk about HIV – is itself hard.

Securing consent and permission from both school and Ministry of Education officials was a stumbling block that made this study's ethical approval process time-consuming and difficult. Gatekeepers were very reluctant to permit me to recruit participants from their schools or ministry. Before I departed from London, the ethics committee of the University of East London required that I seek gatekeepers' approval and identify fieldwork sites, yet my physical absence from Zambia made the process of gaining

ethical clearance very challenging. Engaging agents and a third party to seek permission on my behalf was difficult and time-consuming, and even resulted in permission not being given, as the gatekeepers requested that I as researcher be there in person – which was impossible before the committee could review my ethics applications.

Time and the geographical locations of the researcher and participants were another notable limitation in this study. For example, participants did not get the opportunity to provide feedback on their interview transcripts. None of the participants were requested to comment on my analysis and interpretation of the data although, given time and resources to revisit the fieldwork sites, the research could have benefitted from such input.

In the field, and due to the secrecy that surrounds HIV and living a positive life, some participants were very reluctant to sign the consent form before knowing the kind of questions they were going to be asked, and so they insisted on interviewing first then consenting later – such a contradiction. I also had two female interviewees who did not feel comfortable with being audio-recorded; thus I had to take down key points, with the limitation of not having the transcript to go back through what they had shared during the course of the whole interview.

The one-off interview method may have limited the complexity and negativity expressed by some participants. This limitation, based on my findings, related to mainly positive experiences of physical health, free access to medication, and the enabling medical power of improved ART drugs that have few side effects. Prior work (Nguyen, 2008, 2012) on therapeutic citizenship has not looked at such contradictions, perhaps partly because it has been discursive and ethnographic, rather than focused in detail on individuals' own accounts.

Conceptually, the study also shows how things are, could be or should be, and has some implications for people, specifically professionals, living with HIV, especially in high HIV prevalence contexts; yet global constructions of identity around chronic conditions are difficult to describe uniformly. At the same time, some of the views expressed by participants herein might help us to interpret the living conditions of people living with

other chronic health conditions that require medication in order to manage them, though such conditions also, like HIV, involve their own specificities that need to be addressed.

The shaping of identity is closely related to issues of affect, but the link between identity and affect has not been covered in this research as other important conceptual fields beyond its scope would need to be addressed. Despite its importance, affect is therefore an area of limitation to this thesis's theoretical and empirical attention.

Additionally, the findings in this study cannot be readily generalised from. The small number of descriptive statistics presented involved a sample size too small and, in some cases, data categories too various for statistical tests and any claims to generalizability; but the much larger amount of qualitative findings and the conclusions drawn from them can perhaps be applied in various similar settings. The rigour of this qualitative research entails that the findings and theoretical framework used here have the potential of being transferable to other types of chronic conditions and country specific contexts that can judge what I did in thesis. Transferability of this work to similar situations needs to be done in relation to specific contexts of results and/or through some conceptual foregrounding (Lincoln and Guba, 1985). The research also does not claim to be representative of all HIV positive teachers in Zambia. They are accounts of individuals who willingly participated in this research. Therefore, caution in the interpretation of results and analyses must be considered.

## **8.5 Future research**

Given the key contributions of this thesis, there are essential areas for future research generated through this current study. Several unanswered questions arise, especially concerning the impact of psychosocial factors on civil servants in Zambia growing older with HIV. However, this may require less involvement in academically oriented projects, and more applied research, with medical organisations working alongside social movements in the HIV sector.

Further research should however be done to explore the status of and link between HIV and mental health issues in Zambia. Chapter five revealed that several mental health issues go undetected and untreated, as they are considered to be outside of the diagnostic categories of, for instance, viral load or CD4 count. A study with more focus

on mental health and its relation to the types of citizenship engendered through medicalisation is therefore suggested. In new research, the use of the therapeutic citizenship framework applied here could be a means of understanding the psychosocial influences of HIV treatment.

More work also needs to be done to establish the impact of the interaction between health personnel and HIV service users in Zambia. Since more participants showed a preference for home delivery of ART drugs and talked about negative health personnel experiences, and about exposure while queueing up to collect medication at hospitals as a source of some of the stigma (see chapter five), considerably more work will be needed to determine the viability and feasibility of community-based healthcare provision. It would be informative for HIV service delivery issues to assess client perceptions, and to compare effectiveness between community health workers and state-run hospital health personnel. The reported home ART delivery, by participants, as being based on good adherence record and having an undetectable HIV status, may need a cross-national study involving a sequence of particular case studies. Further studies on this door to door approach to ART services for people living with HIV might help to explore the extent of adherence and levels of stigma experiences in HIV home-based care and delivery of ART drugs to clients' home.

In the findings, the body and changes in physical appearance were a concern attributed to ART's effects by participants; it would also be enlightening to compare people's representations of ART and HIV, and bodily harm and benefit, because ART is often said to make people look healthy and 'fresh' – with actual physiological studies of what happens to people's bodies when on ART.

My findings showed that several participants who talked about a cure also talked about a potential HIV treatment that would not require taking pills at the same time every day, as the latter was tedious, susceptible to forgetting due to reported memory loss issues, socially disruptive, and medically uncertain. As research on a cure continues, it is recommended in the short term – and based on the reported difficulty of taking pills daily, as shown in chapter five – that more studies on injections, patches or non-daily pills for HIV treatment must be done. For instance, trials of weekly or monthly injections for HIV treatment would reduce the medico-social disruption that is caused

by the current daily medication, which was described as denormalising by many of this study's participants. Then a large follow-up study could be done to determine the association between adherence to ART and having a non-daily intake of pills, as well as willingness to start treatment for people who test HIV positive.

Future studies can focus on understanding the relations between HIV experiences and other chronic health condition experiences. Also, relations between biomedicalisation, temporality, sociality, in HIV and with other long-term health conditions can be explored. Additionally, connections between HIV therapeutic citizenship and other kinds of health citizenship; and between HIV and *ubuntu*, versus other conditions and *ubuntu* need to be researched.

Since this study did not fully address the politics of HIV, it would be informative to develop further work that also examines some of the more political elements of my findings. For example, studies on elements of HIV engagement, advocacy, activism, and its relation to other areas of civil society, policy, politics and culture -are required.

## **8.6 Key contributions**

As outlined in chapter one, part of the motivation for this study was the absence of systematic scholarly work that examines contemporary HIV medicalisation in the global south as it appears in people with HIV's own representations of ART, workplace conditions for HIV positive teachers, and also effects of HIV therapeutic citizenship – all, in particular, within a Zambian context. To address these gaps within the research literature, this research sought to provide empirical evidence about and theorisations of the situation of Zambian teachers who are HIV positive. This focus and the approach adopted here to investigate the link between health, education and development in Zambia have not been widely adopted.

Below are key areas of contribution that this study has made to both knowledge and research practices.

The extensive initial careful review of secondary sources led to an initial theoretical framework that included a triad of concepts. Although concepts such as development as well as *ubuntu* did not make part of the key concepts, their application is a separate

thesis ‘contribution’ due to a careful and thorough theoretical review that also led to a frame that guided analysis to some degree but that was also modifiable by the data.

The use of a strong theoretical frame derived from my literature review allowed a lot of openness to what came from the empirical data, which also helped develop the later frame. Additionally, links with non-Western concepts such as ubuntu, although not a main concept in the study, help in understanding some issues in the results that have been omitted from scholarly works that are solely based on non-African philosophical traditions.

The methodological contribution of this thesis lies in how the use of semi-structured interviews uncovers the interconnections between medico-social successes, challenges and prospects of a medicalised lifestyle. These approaches also made possible the discernment of ideas about what constitutes therapeutic citizenship status and its conceptually determined implications for national development in the context of Zambia.

The three-level thematic analytical approach, with some elements of discourse analysis, which this study utilised, allows for a cross-disciplinary study of therapeutic citizenship in the Zambian context.

Thematic concerns around therapeutic citizenship foregrounded here are based on the need to think and contextualise past and recent work on therapeutic citizenship that is not representative of indigenous forms of living. The thematic approach used in this study challenges existing notions of therapeutic citizenship. Here, the focus was on its practical and conceptual incarnation. This research has shown that developments in bioscience are changing current conceptions of citizenship and nationhood. Thus, the findings have strong policy relevance.

Currently, and based on this study’s findings, despite the utility of ART, knowledge and received wisdom about the pandemic are continuously changing. This change in Zambia means that HIV is now a chronic illness that seems to be crafting another layer of citizenship in a therapeutic context. Therefore, the now chronic nature of HIV in

Zambia justifies this as the first major study that has tried to pull together ART representations from different perspective.

Through empirical evidence, theory has been developed further by showing that biomedicine has profound reconfiguration effects on social relations and professional life in chronic living. Not only do the findings point to the fact that biological knowledge has an effect on social and political activities, but they also establish avenues of practice relating to ART processes which create new forms of self and collective identities, as well as a medically predicated sense of belonging.

The research shed more light on areas such as client-health provider interaction and on the mental health problems that often go undiagnosed but need intervention in the era of effective ART outcomes. Moreover, ART appears to have rendered HIV a forgotten disease, yet it still poses new challenges that come with the need for daily treatment.

To the best of my knowledge, this research is the first attempt to offer empirical investigations that seek to explore and examine ART treatment among Zambian teachers.

The conceptualisation of issues in the context of Zambia I made in this research offered a view of the country-specific nature of the epidemic in the treatment era. Also, my findings come from extensive accounts by people with HIV themselves which is not much seen except in work emanating from high-income countries.

The thesis offers new insights into the relationship between development, education and health by determining the extent to which each of these impacts on the others. By pursuing the objectives and addressing research questions through a strong theoretical framework, the study makes a significant theoretical contribution that may be useful in anthropological and sociological fields of study and practice.

The interpretation and analysis of the findings in this study potentially have a wider appeal in terms of applicability and relevance in other contexts of chronic conditions and professions, beyond the specific focus on HIV and teachers. Studies (Dawson-Rose et al., 2016; Stutterheim et al., 2017) do exist on alliances between medical

practitioners, patients and their close relations, yet there seem to be few clear analyses of how these relationships are built up to form individual and collective identities within biomedical discourses. In spite of this research drawing on HIV citizenship, some of the key results and analytical ideas can be applied in understanding health governance and policy interventions for other chronic illnesses. This study offers a strong rationale for further enquiry on how biomedicine and citizenship structure each other.

The previous chapters and sections have analysed and illustrated how and why biomedical advancement in treatment technologies such ART, which draw from the governmentalisation of living with a chronic condition, is providing the material conditions for new forms of citizenship that are shaping individuals and how they relate to others.

## **8.7 Closing statement**

Through semi-structured interviews and three levels of thematic analytical enquiry, this thesis has made a relevant account of what citizenship transformations are taking place in this HIV treatment era in the Zambian context. People living with HIV are now able to make claims as health citizens, drawing on internationally guaranteed positions on rights when national positions on either individual or collective rights are not adequate. Medical science is not neutral, and this study has shown how disruptive technological advancement can be to an individual life, with wider socio-economic implications. The pharmaceuticalisation of HIV as a chronic health condition in the neoliberal era is responsible for a politicisation and marketisation of health and illness that operates at local and international levels (Johnson, 2016; Squire, 2013), especially in the procurement process for ART drugs in low-income countries.

Socially, claims that HIV reshapes identities can be subjective. Hence, biosocial identities can be affected by self-governance in the process of ART adherence. The citizenship forms that emerge among HIV positive individuals are limited and context-based, as not everyone can negotiate their treatment needs within a collective experience or health structure. In this regard, HIV and ART have intersectional effects which mostly draw on social bonds and cultural issues, such as those embedded in *ubuntu* traditions.

Politically, the provision of ART is evidence of what brings people closer to the state. The participants' relationship with the state is enhanced; however, this has created a sense of passivity among HIV community members, as they perceive the state as a benevolent entity. However, *ubuntu* traditions reform this citizenship status into activeness, as being part of the community requires some level of involvement in affairs that affect others.

The results here suggest that most participants have relatively little information about healthy living around HIV treatment, which curtails their possibilities for action. Consequently, ART has the potential to induce passive as well as active HIV therapeutic citizenship through medical, psychosocial and material factors. The extent to which people can withstand hardships in their chronic condition's regimen depends on the state of their social life, mental health, physical health at the start of ART, and available resources, particularly material resources – food, housing, land ownership and many more. Thus, economically speaking, this thesis has shown that those within the middle class face myriad challenges as opposed to possibilities when on ART, due to the latter's nature as an unending medical process laced with uncertainty. Since the SDGs recognise well-being as part of sustainable development, health and development go hand in hand. The findings and conclusions of this research acknowledge that principle, although enforcement depends on policymakers and stakeholders, in Zambia and beyond.

Biomedical 'subjectification' for individuals and institutional (school) situation of self-governance and power relations can be challenging to reconcile for HIV positive teachers. Having a medicalised Zambian teaching profession with low salaries, promotion barriers and lack of full representation for those who are living on ART and affected by HIV can compromise capabilities for quality pursuance in the education system for development purposes in the country. This thesis has shown that living a life mediated by medicine leaves individuals, including teachers, in positions of uncertainty, despair and periodic disruptions of self-efficacy.

The narrowing of well-being by medicine restricts the normalisation of HIV to clinical approaches, leaving out physical and psychosocial concerns. Thus, by repurposing therapeutic citizenship in the biomedical and biosocial context, this study has added to

the existing literature through empirical data and the use of an integrative conceptual approach to the politics and sociology of medicine, health and illness. Although HIV is no longer considered a crisis, it remains an agenda that is unfinished. It will be more difficult if not impossible to normalise HIV chronicity, medically and socially, than was the case in previous decades of the pandemic crisis in low-income countries such as Zambia. If the treatment of HIV as a chronic condition with long-term effects is poorly dealt with, especially among important groups such as teachers, another complex wave of devastation will be unleashed. Therapeutic citizenship may be not just about activism or claims-making but also about communal ways of living with HIV, or any other form of chronic health condition, for citizens and specific groups in a nation. As demonstrated in the findings and literature reviews, and given the socio-economic implications of HIV's chronicity, there is no room to escape the demands of therapeutic citizenship. These demands include such issues as the structures of administration and self-management with which people who are HIV positive or affected by HIV – such as Zambian teachers – must live in the ART era.

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## Appendices

### *Appendix 1: Researcher introduction letter*

March 20, 2017



### **Subject: Application for Permission to Collect Data for Academic Purposes**

Dear Sir/Madam,

#### **Project Title:** *A Study on Zambian Teachers' Everyday Life, HIV and Health*

I am a UNZA lecturer working in the School of Education, Department of Language and Social Sciences Education. I am pursuing my PhD studies with the University of East London. Therefore, I am currently looking for potential participants who are willing to take part in this study whose title I have stated above.

Participants in this study will not be identified and they will remain anonymous since I will be asking questions just about everyday life. Taking part in this research will be on voluntary basis and respondents will be free to discontinue their participation in the study at any point. For any unexpected outcome such as fatigue or distress during and after the interview process, referrals for help will be available.

Therefore, I am seeking permission from your office to identify and recruit participants at your site. This will be an opportunity for participants to share their views on the subject and the feedback will be empowering as it will explore people's strength.

For further clarification on this study, please do feel free to get in touch with me or **Catherine Fieulleateau, Research Integrity and Ethics Manager**, Graduate School, EB 1.43 University of East London, Docklands Campus, London E16 2RD  
Telephone: 020 8223 6683, Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)

Yours faithfully,

A handwritten signature in blue ink that reads 'Sanny Mulubale'.

**Sanny Mulubale**

PhD Research Student,

The University of East London, Graduate School.

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**Director of Studies**

Professor Corinne Squire  
EB 1.59 Docklands Campus  
University of East London  
School of Law and Social Sciences  
Docklands Campus  
London  
E16 2RD

Phone: +44282232686 Email: c.squire@uel.ac.uk

**Student researcher**

Sanny Mulubale  
1D Bingley Road, London, E16 3JR  
Phone: +447721072836 Email: u1539411@uel.ac.uk

**Consent to Participate in a Research Study**

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.



## **Project Title**

A Study on Zambian Teachers' Everyday Life

## **Project Description**

I am a PhD student at the University of East London and currently collecting data for a study whose aim is to explore how Zambian teachers are living long-term with Antiretroviral Treatment.

Would you be willing to take part? If so, please get in touch so we can discuss. I am very interested to hear your opinion and experiences about this issue, how things are going, how they could be better, what the difficulties/challenges are, and what have been the improvements.

The study will involve a one – to – one interview which will last between 20 to 50 minutes. Participants will be free at any time to take a break. If you decide to discontinue the interview, you are free to excuse yourself and stop the interview at any time. I will be asking questions just about everyday life. Should you want more information or feel worried in the interview, I will be in touch with services that can help you.

The interview will be conducted in a distraction-free place and where you as a participant will prefer.

## **Confidentiality of the Data**

In order to maintain privacy, the interviews will be anonymous. I will be asking for some general information about you – for instance, gender and age. The interview will be identified only by a number.

The interviews will be treated with utmost confidentiality. Participants will be cited anonymously. This study is being conducted at University of East London and is not linked to any Zambian schools or Ministry of Education.

The data collected will be saved on an encrypted and password (known by me only) protected device. The data will not be saved or stored on public computers or printed by any other party besides the researcher student. The memory devices or computer with the data will be locked up in a safe locker at all times.

The data will be interpreted and will be used for a PhD Thesis and published through a peer reviewed journal, book and might be presented at conferences and workshops. There will be no identifying information in any of these papers or presentations.

The data generated during this research will be retained in line with the existing University's Data Protection Policy.

### **Location**

The study is being carried out in Lusaka and Western parts of Zambia.

### **Remuneration**

There will be no payment for taking part in this study. Apart from transport expenses, incurred if any, by the participants to their preferred and most convenient place of being interviewed. But as a participant you have an opportunity to share, in peaceful manner, your views on living with HIV and on antiretroviral treatment. I also hope that this study will help others living with and affected by HIV, especially teachers.

### **Disclaimer**

Your participation in this study is entirely voluntary, and you are free to withdraw at any time during the research. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a reason.

### **University Research Ethics Committee**

If you have any concerns regarding the conduct of the research in which you are being asked to participate, please contact:

**Catherine Fieulleateau, Research Integrity and Ethics Manager, Graduate School, EB 1.43  
University of East London, Docklands Campus, London E16 2RD  
(Telephone: 020 8223 6683, Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk))**

For general enquiries about the research please contact the Principal Investigator on the contact details at the top of this sheet.



**UNIVERSITY OF EAST LONDON**

**Consent to Participate in a Programme Involving the Use of Human Participants.**

[PhD in Social Sciences via MPhil]  
[Sanny Mulubale]

Please tick as appropriate:

	YES	NO
I have read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.		
I am aware that this interview will be audio recorded and I approve to being recorded as a participant.		
I understand that my involvement in this study, and particular data from this research, will remain confidential. Only the researchers involved in the study will have access to the data.		
I understand that maintaining strict confidentiality is not subject to any expected or unexpected limitations. This implies that participants' confidentiality will strictly be maintained regardless of any study limitations.		
I understand that where direct quotations are made in publications, reports or presentations, quotes will be anonymised and other identifying information will be removed.		
I understand that findings of this study will be disseminated through academic journals, conference proceedings, in books and will be archived.		
I permit the re-use of the data obtained from me in future research and education work.		
I am in agreement to be re-contacted for future studies by this researcher.		
I understand that my participation in this study is entirely voluntary, and I am free to withdraw at any time during the research without disadvantage to myself and without being obliged to give any reason.		

I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications and archives.		
--	--	--

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Investigator's Name (BLOCK CAPITALS)

.....

Investigator's Signature

.....

Date: .....

*Appendix 3: Ethics approval letter*



25<sup>th</sup> April 2017

Dear Sanny,

<b>Project Title:</b>	<b>Identity, Governmentality, Chronicity and Development: A Study on Zambian Teachers Living with and affected by HIV and 'Therapeutic Citizenship'</b>
<b>Principal Investigator:</b>	<b>Professor Corinne Squire</b>
<b>Researcher:</b>	<b>Sanny Mulubale</b>
<b>Reference Number:</b>	<b>EXP 1617 09</b>

I am writing to confirm the outcome of your application to the University Research Ethics Committee (UREC), which was considered by UREC on **Tuesday 25 April 2017**.

The decision made by members of the Committee is **Approved**. The Committee's response is based on the protocol described in the application form and supporting documentation. Your study has received ethical approval from the date of this letter.

Should you wish to make any changes in connection with your research project, this must be reported immediately to UREC. A Notification of Amendment form should be submitted for approval, accompanied by any additional or amended documents:  
<http://www.uel.ac.uk/wwwmedia/schools/graduate/documents/Notification-of-Amendment-to-Approved-Ethics-App-150115.doc>

Any adverse events that occur in connection with this research project must be reported immediately to UREC.

**Approved Research Site**

I am pleased to confirm that the approval of the proposed research applies to the following research site.

<b>Research Site</b>	<b>Principal Investigator / Local Collaborator</b>
Zambia's Lusaka and Western provinces	Professor Corinne Squire

## Approved Documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
UREC application form	3.0	25 April 2017
Participant Information sheet	3.0	25 April 2017
Consent form	3.0	25 April 2017
Interview questions guide	1.0	23 March 2017
Application for Permission to Collect Data for Academic Purposes	1.0	23 March 2017
Permission to collect Data from Mulambwa Basic School	1.0	23 March 2017
Permission to collect Data from Northmead Secondary School	1.0	23 March 2017
Permission to Collect Data from Senanga Day Secondary School	1.0	23 March 2017
Permission to Collect Data from Senanga Boarding Secondary School	1.0	23 March 2017
Permission to Collect Data from Matauka Secondary School	1.0	23 March 2017
Permission to Collect Data from Namalangu Day Secondary School	1.0	23 March 2017
Permission to Collect Data from Munali Boys Secondary School	1.0	23 March 2017
Application for permission to collect data for academic purpose - Mongu Western Province	1.0	23 March 2017
Confirmation of financial support from Commonwealth Scholarship Commission in the UK	1.0	23 March 2017
Notification of award from Commonwealth Scholarships	1.0	23 March 2017
Training Contract from the University of Zambia	1.0	23 March 2017

Approval is given on the understanding that the [UEL Code of Practice in Research](#) is adhered to.

The University will periodically audit a random sample of applications for ethical approval, to ensure that the research study is conducted in compliance with the consent given by the ethics Committee and to the highest standards of rigour and integrity.

**Please note, it is your responsibility to retain this letter for your records.**

With the Committee's best wishes for the success of this project.

Yours sincerely,

A handwritten signature in black ink that reads "Fernanda Silva". The signature is written in a cursive style with a large initial 'F'.

Fernanda Silva  
Administrative Officer for Research Governance  
University Research Ethics Committee (UREC)  
Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)

*Appendix 4: Sample of gatekeeper approval letter*

*All correspondence to be addressed to the  
Headteacher*

**Tel:0217-221137**



*In reply please quote:*

*No.....*

**REPUBLIC OF ZAMBIA**

# **MINISTRY OF EDUCATION**

**MULAMBWA BASIC SCHOOL  
P.O.BOX 910143  
MONGU-ZAMBIA  
WESTERN PROVINCE**

3<sup>rd</sup> April, 2017.

Dear Sir,

**REF: AUTHORITY TO DO A RESEARCH AT THE ABOVE MENTIONED SCHOOL.**

I refer to the above subject.

I write to inform you that as a school we have no objection to your request.

Kindly be informed that you are welcome to do your research.

Yours faithfully,

A handwritten signature in blue ink, consisting of a stylized 'O' followed by a horizontal line.

**O. Mubandi  
HEADTEACHER**



### Teachers Living with and affected by HIV and Therapeutic Citizenship

What motivates you in life? **Prompt:** *your interests, feeling best about yourself.*

What terms would you use to best describe yourself as a person? **Prompt:** *different person, same like always or before. Feeling and seeing yourself differently circumstances, or when you are with certain individuals? Prompt: family, friends, and workmates?*

What do the terms ‘illness’ and ‘health’ mean for you? **Prompt:** *thinking about the health of your body. Seeing yourself as being ill.*

How can you describe the experiences of taking medicine and what do ARVs mean for you? **Prompt:** *physically, emotionally, and mentally, words or terms, images, nickname come to mind.*

On a day – to – day basis, how do you deal with living on medicine and HIV? **Prompt:** *do you have strategies that help? Ways of coping, practical, mental.*

How does living in HIV and medication affect your routine activities? **Prompt:** *bothered by any limitations of performing daily activities like teaching? But also beyond this; caring responsibilities with children, elderly relatives, maintaining the house, earning money outside of teaching, farming etc. Effectiveness of (western) medicine you are taking - any positive and negative elements?*

Would you say you have support from others that you need? **Prompt:** *From Family, Friends, NGOs, School, Ministry of Education/ Government, Media, Religion, Medicine Access, how is this not/affected by disclosure.*

What are your thoughts about the future? **Prompt:** *as a teacher on ART, finances, relationships, worry of physical pain, death.*

Is there anything else you would want to share with me?

Participant #	Date	Time	Locality (Urban/Rural)
Province	Gender	Age	Years of Teaching

Appendix 6: Participants' demographic information

<b>NVivo Script #.</b>	<b>Participant Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Teaching years</b>	<b>Education</b>	<b>Location</b>
P 13	Luyando	Female	55	2 council	Pilot	Urban
P 2	Mate	Male	59	26 council	Pilot	Urban
P 4	Wamui	Male	59	20 council	Pilot	Urban
P 5	Likezo	Female	57	30 nurse	Pilot	Urban
P 1	Emonda	Female	35	1	Diploma	Urban
P 3	Sitwala	Female	53	29	Diploma	Urban
P 6	Mwaka	Female	43	19	Diploma	Urban
P 7	Njamba	Male	37	13	Diploma	Urban
P 8	Mwangala	Female	49	21	Diploma	Urban
P 9	Sibeso	Female	55	36	Diploma	Urban
P 10	Chipo	Female	37	11	Diploma	Urban
P 11	Sililo	Male	35	15	Degree	Urban
P 12	Lulu	Female	47	27	Diploma	Urban
P 14	Nandi	Female	54	34	Diploma	Urban
P 15	Namenda	Female	34	10	Diploma	Rural
P 16	Lugowe	Female	32	9	Diploma	Rural
P 17	Nalu	Female	31	6	Diploma	Rural
P 18	Mbaeta	Female	33	7	Diploma	Rural
P 19	Beenzu	Female	46	20	Diploma	Rural
P 20	Mudenda	Female	39	9	Diploma	Rural
P 21	Maata	Female	46	18	Diploma	Rural
P 22	Choolwe	Male	38	17	Diploma	Rural
P 23	Mutukwa	Male	39	12	Diploma	Rural
P 24	Lilato	Female	42	9	Diploma	Rural
P 25	Silishebo	Female	49	28	Diploma	Rural
P 26	Miyanda	Female	43	14	Diploma	Rural
P 27	Pumulo	Male	48	24	Diploma	Rural
P 28	Pekelo	Female	37	7	Diploma	Rural
P 29	Lutangu	Female	40	12	Diploma	Rural
P 30	Sitondo	Male	42	19	Diploma	Rural
P 31	Mweetwa	Male	42	12	Diploma	Rural
P 32	Mundia	Male	27	4	Certificate	Rural
P 33	Sumbwa	Male	39	10	Diploma	Rural
P 34	Monga	Male	45	12	Diploma	Rural
P 35	Likando	Male	28	1	Certificate	Rural
P 36	Moola	Male	51	25	Diploma	Urban
P 37	Milimo	Male	30	6	Diploma	Urban
P 38	Kalaluka	Male	49	27	Diploma	Urban
P 39	Mukela	Male	31	5	Diploma	Urban
P 40	Michelo	Male	49	3	Diploma	Urban
P 41	Sikota	Male	52	10	Diploma	Urban
P 42	Muna	Male	42	20	Diploma	Urban
P 43	Hamuntu	Male	37	14	Degree	Urban
P 44	Mweemba	Male	39	2	Degree	Urban
P 45	Ngolwa	Male	52	32	Diploma	Urban

Appendix 7: Year of HIV diagnosis and treatment commencement

Female			Male		
Participant pseudonym	Year of diagnosis	Treatment year	Participant pseudonym	Year of diagnosis	Treatment year
Likezo	pilot		Wamui	pilot	
Luyando	pilot		Mate	pilot	
Mwaka	2004	2004	Sililo	2015	2016
Emonda	2014	2014	Njamba	2013	2013
Mwangala	2007	2007	Choolwe	2006	2007
Sibeso	2006	2009	Mutukwa	2015	2015
Chipo	2008	2009	Pumulo	2016	2017
Lulu	2006	2007	Sitondo	2010	2010
Sitwala	2006	2006	Mweetwa	2015	2015
Nandi	2008	2010	Mundia	2015	2015
Namenda	2010	2017	Sumbwa	2009	2009
Lugowe	2016	2016	Monga	2013	2013
Nalu	2016	2016	Likando	2011	2011
Mbaeta	2005	2017	Moola	2004	2004
Beenzu	2005	2005	Milimo	2014	2014
Mudenda	2009	2014	Kalaluka	2003	2003*
Maata	2004	2004*	Mukela	2014	2014
Lilato	2014	2014	Michelo	2004	2004
Silishebo	2007	2016	Sikota	2014	2014
Miyanda	2007	2009	Muna	2012	2012*
Pelekelo	2005	2007	Hamuntu	2014	2015
Lutangu	2007*	2007	Mweemba	2016	2017
			Ngolwa	2007	2007

## Data Protection Policy

### General Data Protection Regulation (EU) 2016/679 & Data Protection Act 2018

#### Summary

- The Data Protection Act 1998 is being replaced by the Data Protection Act 2018, which is based on the General Data Protection Regulation
- The new law applies to data that can identify a person – personal data.
- Some data is particularly sensitive such as ethnicity or medical data; this is considered ‘special category’ data.
- This policy explains how the University meets its obligations under the Data Protection Act, outlines the **responsibilities of staff and students** and provides information on the information rights associated with how personal data is managed. Complying with this policy is a condition of employment or study at UEL.
- This policy forms part of the wider Data Protection Framework that has designed to ensure ongoing compliance with Data Protection law and the implementation of data protection best practices across the institution.
- UEL has a legal obligation to only process personal data in line with the data protection principles
- UEL must also provide information about any processing of personal data taking place and ensure that individuals are aware of and can exercise their information rights.
- Individuals about whom personal data is being processed have rights concerning how their personal data is managed.
- All staff, students and third parties associated with UEL have a responsibility to ensure that they keep personal data secure, only share it when authorised to do so and only use personal data for the purpose it was collected.

- Any students that process the personal data of others as part of their course are subject the same stipulation and to the relevant points in this policy.
- In the event of a data breach or a suspected breach, staff and students have a responsibility to notify the Data Protection Officer or appropriate member of staff as soon as possible.
- Misuse of data or negligent disregard for the obligations contained within the Data Protection Act, are criminal offences.
- Any queries relating to the privacy policy, or any concerns relating to data protection at UEL should be sent to [dpo@uel.ac.uk](mailto:dpo@uel.ac.uk) in the first instance.

## Introduction

This policy applies to all research, funded or unfunded, created by UEL academics and research postgraduate students. It applies to all disciplines, including those in the arts and creative areas.

The University of East London (UEL) recognises that quality research demands effective data management in the support of academic integrity, openness, and good information governance. UEL will ensure that research data is managed to high standards throughout the research data lifecycle<sup>1</sup> as part of its commitment to academic excellence. This policy will ensure that UEL acts in accordance with UK Research and Innovation's *Common principles on data policy*<sup>2</sup>, requirements of funding bodies, and general best practice.

It should be viewed in conjunction with the Code of Practice for Research Ethics, the Policy on Intellectual Property, the Data Storage & Retention Policy, and the Open Access Policy.

## Definition

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts or prototypes that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects. Examples include, but are not limited to, the following:

- Statistical data held in spreadsheets or databases
- Test, survey or questionnaire responses
- Interview transcripts
- Notebooks and fieldbooks
- Laboratory test results
- Prototypes
- Audio and video recordings
- Photographs
- Specimens or samples
- Artefacts
- Algorithms and scripts
- Drafts or earlier versions of creative outputs, such as works of art or musical compositions

## Research Data Management

1. Research data created by UEL staff and research postgraduates must be managed in compliance with UK Research and Innovation's *Common principles on data policy* and other relevant community standards throughout the research data lifecycle as part of UEL's commitment to academic excellence.
2. Primary responsibility for compliance with this policy lies with Principle Investigators (PIs) or UEL lead investigators where the PI is not employed by UEL. For research postgraduates, primary responsibility lies with the student themselves.
3. Directors of Research will support and advocate for compliance with this policy. They will make arrangements for stewardship of datasets in the absence of PIs.
4. Library & Learning Services provide advice and guidance on best practice for managing research data and adhering to funder requirements and the requirements of this policy.
5. Library & Learning Services, supported by IT Services, provide the systems and technical infrastructure required to support this policy. This comprises UEL's research data repository (data.uel), as well as data backup and archiving. This infrastructure ensures the long term integrity of UEL's research data and ensures that funder requirements for secure storage and sharing of data can be fully met.

## Data Management Plans

6. Any research that generates empirical or statistical datasets or any other type of digital object must have a data management plan (DMP). All externally-funded research must have a DMP if required by the funder. A DMP is strongly advised for all other research. The completion of a DMP is the responsibility of the PI.
7. Any research that requires approval from the University Research Ethics Committee must have a DMP. This is a mandatory condition of the ethics approval process.
8. Research postgraduates must create a DMP if their research will generate empirical or statistical datasets or any other type of digital object. DMPs are strongly advised for all research conducted by research postgraduates. Responsibility for this lies with the student.
9. DMPs for funded research should adhere to the requirements of the funding body. Unless other guidelines from a funding body apply, DMPs should adhere to the guidelines in Annex A of UKRI's *Common principles on data policy*. Library & Learning Services provide advice on DMP best practice.
10. Library & Learning Services and Research & Development Support (ReDS) must be provided with access to a copy of all DMPs.

## Management of 'live' research data

11. Anyone engaged in research at UEL must take all appropriate steps to ensure the security and integrity of research data as it is generated and worked upon. Instructions and requirements documented in the DMP must be adhered to at all times. Library & Learning Services and IT Services provide advice and guidance on management of live research data.

## Depositing research data

12. Depositing data has important benefits for researchers, UEL, and the wider scholarly community. Deposited data is protected and safeguarded, ensuring it is available for future consultation or reuse.
13. All data must be deposited in a data repository where appropriate and the depositing arrangements specified in the DMP must be adhered to. Library & Learning Services provide further advice on whether it is appropriate for data to be deposited.
14. Data should be deposited in UEL's data repository (data.uel) unless an external repository has been specified by a research funder, or unless the PI or research postgraduate wishes to deposit in an alternative repository (e.g. a discipline-specific repository). Library & Learning Services must be informed of all datasets deposited somewhere other than data.uel so that a record linking to that dataset's location can be created.
15. Data should be deposited as soon as is practicable after the completion of the research and generally no later than the publishing of the results. Any timescales for upload imposed by external funders must be adhered to. It is recognised that time may be required to prepare data for deposit (e.g. to carry out anonymisation), but this must not unduly delay the deposit of the data, or its release where appropriate.
16. Researchers are responsible for preparing research data for depositing. Library & Learning Services provide advice about preparation.
17. Where UEL is not the lead institution, it is expected that the lead institution will take responsibility for depositing the data in an appropriate repository. UEL will not add a duplicate of the dataset to data.uel, but will create a record linking to the dataset's location.
18. A Digital Object Identifier (DOI) will be assigned to datasets stored on data.uel to enable effective citation, discovery, and access. Data will be linked to relevant outputs in UEL's open access publications repository, ROAR.
19. There is a presumption of releasing data created at UEL, with appropriate safeguards, in order to meet regulatory and contractual requirements. All data should be fully released, with appropriate safeguards, including secure dissemination, unless there are specific reasons to prevent this.

20. Personal or sensitive data must be anonymised where it is appropriate for release in other respects. It is recognised that there will always be some data too sensitive for general release, even with anonymisation. The UEL Data Protection Officer provides advice and guidance on what is inappropriate for general release.
21. In all cases, the legitimate interests, rights, and freedoms of participants must be protected in line with data protection legislation and research ethics approval.
22. Library & Learning Services supports researchers in creating appropriate and high quality metadata, which will enable other researchers to understand the research and the re-use potential of the data. Where data cannot be made available openly, the metadata should state the reasons why.
23. Data must be appraised (reviewed) at the end of the research project and every 5 years thereafter, unless another timescale is specified by the research funder, until the data are transferred or destroyed. PIs are responsible for ensuring this is carried out and for taking any decisions about whether data should be transferred or destroyed. If the PI has left UEL, this responsibility will fall to the relevant Director of Research. Advice may be sought from Research and Development Support (ReDS), Library & Learning Services, and UEL's Data Protection Officer. In any cases where there is disagreement over whether data should be destroyed, the Pro-Vice Chancellor (Impact & Innovation) will take the final decision.
24. Library & Learning Services will assist PIs in transferring data to external services where appropriate and record any transfers and destruction of datasets.
25. Exclusive rights to reuse or publish research data should not be handed over to commercial publishers without retaining the rights to make the data openly available, unless this is a condition of funding.
26. Library & Learning Services will provide reporting on this policy and its implementation to the Research & Knowledge Exchange Committee and other bodies as appropriate.
27. All UEL-led research, regardless of format, duration, funding, or collaboration must adhere to all relevant UEL policies. Failure to do so may result in the removal of ethics approval, support, or the premature closure of a project.

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<sup>i</sup> Digital Curation Centre (n.d.) *DCC curation lifecycle model*. Available at <http://www.dcc.ac.uk/resources/curation-lifecycle-model>

<sup>ii</sup> UK Research and Innovation (2015) *Common principles on data policy*. Available at <https://www.ukri.org/funding/information-for-award-holders/data-policy/common-principles-on-data-policy/>

Appendix 9: Risk assessment form

 <b>UEL Risk Assessment Form</b>			
<b>Name of Assessor:</b>	<b>Sanny Mulubale</b>	<b>Date of Assessment</b>	<b>20/02/2017</b>
<b>Event title:</b>	<b>Collection of Data</b>	<b>Date, time and location of activity:</b>	<b>Zambia (Southern and Western Provinces)</b>
<b>Signed off by Manager (Print Name)</b>			
<p><b>Please describe the activity in as much detail as possible (include nature of activity, estimated number of participants, etc) If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:</b></p>			
<p>This exercise of data collection will be done through semi-structured interviews. These will be guided by the interview question guide though participants will themselves guide the interviews. The participants will be purposively and conveniently sampled. The interviews will be voice recorded and the analysis of the data collected will be thematic; this will allow the study to arrive at its own synthesis. It is planned to include elements of ethnography in this study, in the form of informal conversations on the topic, in educational and other everyday settings. These elements will allow attention to broad discursive data. The tabulation will be as follows: 30 teachers (15 males and 15 females) of any age range who may be from either an urban or rural locality and are HIV positive, diagnosed over six months, and in work or living at home that is not acutely ill.</p> <p>It is also intended that the sample can be expanded to other 20 teachers - drawn from selected schools - (10 males and 10 females) who are not HIV positive but are willing to talk about HIV, if recruitment of HIV positive teachers proves difficult. In the event that the planned number of HIV positive teachers is not met due to the 'secrecy and sensitivity' that surrounds the subject, then teachers who are not HIV positive but are willing to share their perspectives on the topic will be invited to take part in the study.</p>			
<b>Overview of FIELD TRIP or EVENT:</b>			
<p>The fieldwork is aimed at collecting data in relation to <b>Zambian Teachers Living with and affected by HIV and 'Therapeutic Citizenship'</b>.</p>			

**Guide to risk ratings:**

<b>a) Likelihood of Risk</b>	<b>b) Severity of Risk</b>	<b>c) Risk Rating (a x b = c)</b>
------------------------------	----------------------------	-----------------------------------

1 = Low (low or minimal risk)	1 = Slight (minor injury)	1-2 = Minor = No action required
2 = Moderate (small change = accident)	2= Moderate (injury or disease)	3-4 = Medium = May require control measures
3 = High (100% certain to occur)	3 = High (death or serious injury)	6-9 = High = Must Implement control measures

Which Activities Carry Risk?								
Activity / Task Involved	Describe the potential hazard?	Who is at risk?	Likelihood of risk	Severity of risk	Risk Rating (Likelihood x Severity)	What precautions have been taken to reduce the risk?	What further action is needed to reduce risk (By whom and by when?)	Review Date
<b>Conduct interviews in the fieldwork</b>	Interviewees may demand monetary or material compensation for taking part in the study.	The researcher and gatekeepers from HIV support groups or organisations.	1	1	1	Participants will consent to the non-availability of remuneration before taking part in the study.	Participants' travel expenses in return for their time and participation in the study will be covered by the researcher, however no extra recompense will be offered.	1/3/2017
<b>Interview</b>	Worry, Fatigue	Participant	1	1	1	Interview questions have been formulated to be as open ended as possible. Participants will be free to stop the interview and take breaks. Will have food and drinks.	Participants who experience unease in the interview process or who require further information will be referred to professional counsellors and advice services with which the research	1/3/2017

A comprehensive guide to risk assessments and health and safety in general can be found in UEL's Health & Safety handbook at <http://www.uel.ac.uk/hs/hs-handbook.htm> and a comprehensive guide to risk assessment is available on the Health & Safety Executive's web site at <http://www.hse.gov.uk/risk/casestudies/index.htm>. An example risk assessment is also included below.

*Appendix 10: Sample of interview transcripts*

**Nandi (P14)**

- I: Like I said this study talks about the everyday life of people living on medication and how you are managing as a teacher. Also, some of the things you think would be approved to make life much better. Thank you very much for your time. Let me start with issues of motivation. What motivates you in life?
- RF: What motivates me is just the passion I have for a child. As a teacher I have passion for that child. It really motivates me because it took my parents to take me to school for me to help other people. So, when I see a child, I just get encouraged and wake up every day to come and meet the needs of a child.
- I: What things make you feel best about yourself?
- RF: I'm one of the persons that are HIV positive but it's funny that every day I feel low and I feel the pain.
- I: Every day?
- RF: Yes, every day, but when I wake up in the morning I feel better. When I mix with other people I feel much better, but I will be sick when I go back home this evening. I really don't know how I can describe myself.
- I: Tell me something about what makes you feel bad about your situation, what triggers that? Why do you have negative feelings about your condition every day?
- RF: I used to be very fine and I could do every kind of work. But since I started taking medication, I am not that fine.
- I: Do you see yourself as a different person from who you used to be?
- RF: I am totally different.
- I: How are you different?
- RF: I am gaining weight; this is not how I used to look like.

I: You have put on weight?

RF: Yes, I have put in extra weight. This is not the weight I never used to have. I can't do heavy you to work, I get tired easily.

I: How long have you been on treatment?

RF: This is my 7<sup>th</sup> year.

I: Have you changed the type of medicine you're taking now?

RF: When I started the first dose, it made my blood pressure very high. I already had high blood pressure, but the medicine made it worse such that I almost became blind. The second one made me feel as though my body was on fire after 30 minutes of taking it. I had to discontinue the drug as well. The third one I'm on is Truvada and Thorazine. I take it in the morning and in the evening. I am much better, although I feel as if my body and I am in pain, I really do not know.

I: Have you talked to your doctor?

RF: The doctor says I have to reduce my weight. Now how do I use the weight?

I: Do you think the physical challenges you are going through a as a result of your medication?

RF: Obviously. People say I look fine, but I know I look awkward.

I: Do you think you really look awkward or it something mental?

RF: It could be mental in the sense that this is not how my body should look like and feel. I have been bloated and I'm sick. I ask myself, "couldn't be the pills I am taking?" Some people that take this drug and become healthy. Some people do not complain even though they take this medication. I'd not have an answer for these questions.

I: How best would you describe yourself as a person right now?

RF: For now, I described myself as a living testimony. I'm a human being who is just living on God's grace. If death came, I am ready for it. I have done what I can do, and I am already in this predicament which I can't come out of. Either I take it or leave it. I have to take it and life has to go on.

- I: Do you see yourself different when you are with your friends?
- RF: When I came to the school I was sidelined. The people would not accept me. I whispered to my deputy that sometimes I lose memory. I say to her as my counterpart help me because I might one day leave a check on the table and go to the bank without it. I asked her to be reminding me when I forget certain things. I told her my position in life, I am HIV positive. But she took the information to every teacher and they would laugh at me. I said well and good you can tell the whole world.
- I: In what capacity did you come to the school?
- RF: I came as the head. Our DEBBS tells us to tell our immediate subordinate about our condition so that they understand. This is what we have also told the teachers. Some have come to tell me that they are sick, but others have decided to hide and it's not my business. I know some are taking medicine but it's none of my business. Some of us have come out openly and I'm proud to tell my teachers that I am leaving positively. If God calls me, I'm I am done. I pray that I live to enjoy my pension that I have worked for so many years. I was about to retire in 2014 then I was giving 5 more years.
- I: You talked about memory loss. Do you think it is as a result of the medication?
- RF: Yes, when I started it gave me a lot of tension. I would lose my memory and just feel blank in my mind. It took about 6 months for me to stabilize.
- I: But how are you now?
- RF: I am okay now although my feet are painful, and I cannot put on closed shoes.
- I: How would you define it illness?
- RF: Illness is being down such that you can do what you are supposed to do, and the body is weak. Sometimes it's because someone does not have a balanced diet that's why they get sick. As HIV positive people we are advised to eat balanced meals. But the money that they get cannot allow me to buy the food I need to eat.
- I: So, you do not have a balanced diet?

- RF: No, I do not think so. We eat whatever we can manage to buy. I can't have what I need to eat.
- I: Would you consider yourself to be ill?
- RF: Yes, I consider myself to be ill, but I do not show it.
- I: What's your understanding of being healthy? How would you define health?
- RF: When someone has no complaints and they're able to execute their duties every day they have a good diet, and everything is going on well with them then they are healthy.
- I: So, you see yourself to be ill?
- RF: Yes, I do. I see no light at the end of the tunnel.
- I: But you are able to work and do your duties?
- RF: Yes, I work but with a lot of challenges because I have no choice but to work.
- I: How would you describe the experiences of taking medicine?
- RF: Taking medicine is not an easy thing. It's more like suicide. If you take the medicine you will live, if you don't you will die. I have seen some people who disrupted taking the medicine and they died like animals. Being the head teacher is a testimony to me. I tell those that are positive to just take the drugs. I tell them the side effects and explain that for this first 6 months they will be sick but afterwards or will be fine. Taking medicine is not an easy thing. If it was injectable I think it would be better for me. If we could be injected for a year like it is done for family planning and then go for the other year. Taking pills every single day is not easy. Sometimes I forget especially when I'm out of my home. I should take medicine at 18 hours. It's already 18 hours and I am still here at work. So, taking drugs every day is not easy, one needs to be disciplined. Wherever you go you need to have the medicine in the bag. It is more like a demon we are worshipping.
- I: What do ARVs mean for you? When you hear the abbreviations ARV, what name comes to mind, what nickname or image comes to mind?
- RF: What I understand is that these drugs are there just to protect us.

- I: Do you have a slogan or a name that you have given the tablets?
- RF: No I do not have anything in mind and I do not think about it. I live positively no matter what. If you think about it too much you die easily. Some people die even out of fear. So, I am moving on.
- I: On a day to day basis how do you deal with being on medicine and living with the virus? Do you have a strategy that helps you cope with some of the challenges that come your way?
- RF: I can't express much because I just depend on the medicine.
- I: So, you don't have any strategy that helps you adhere to the medicine?
- RF: No, it's just the medicine and eating food. I have a good appetite and so I need to eat.
- I: How has being on treatment affected your routine activities? Do you have any limitations or are you bothered by the medicine?
- RF: The medicine has made me feel too weak to work as hard as I want to. I can't do heavy duty work anymore. I can sit and give commands, but I cannot run or do anything of that sort. If I want to run I can just do a bit of jogging.
- I: Outside just teaching and being the head teacher, do you think that you are limited by being on treatment to engage in co-curricular activities?
- RF: I am a preacher, I do preach at church, and I have not disclosed my status at church. I have only disclosed to my work mates. But because of the way I look some people guess that I'm sick. To tell you the truth, the medication has made my body weak.
- I: Why haven't you disclosed at church?
- RF: Its pushing because they're many people that are not mature. If I tell them they will be talking about me. I look at the maturity and I realize they can't take this information.
- I: Has the medication affected your responsibility in terms of taking care of your relatives, your children and making money outside teaching?

- RF: I used to do cross boarder trading, but I can't anymore because of the medication. I cannot sit for a long time I need to be comfortable. I come from Northwest Province, but I do not go there often I only go when there is a funeral. I need clean water and a comfortable place. As a human being, there are issues I need to attend to let so sometimes I just have to strain myself and do that. If I don't do that some people might not understanding. But inwardly its eating me up.
- I: When you say its eating you up, what exactly do you mean?
- RF: I mean going through the pain every day because the body is weak and it's not fine.
- I: What is the state of your mind or your mental health?
- RF: My mental health seems to be somehow dilapidated. I look at my children, my parents, my grandchildren and I said to myself, suppose I die, how will they leave? I am sick and living on these drugs and one day I will die prematurely. Because these drugs can carry you when they reach the maximum and you die. I am just preparing for the future.
- I: Do you know any person that has passed on because of the drugs they were taking?
- RF: I have not to come across any person that died because they were taking the drugs as they're supposed to. The ones that have died are those who stopped taking the drugs.
- I: How effective have the drugs been? Do you have negative and positive elements?
- RF: I have positive elements. I am not sick now the way I used to be those days this time I am fine even though I complain I am fine.
- I: Would you say you have received support from others like you family, the church, NGOs and the school?
- RF: No, I haven't, not at all.
- I: have you disclosed your status to your family?

RF: My children and my husband know.

I: Have they supported you in anyway?

RF: No. They don't even believe it. They think mom is just a dramatist.

I: So, you have totally not received any form of support?

RF: No, I haven't.

I: Not even from NGOs?

RF: No.

I: How has the issue of disclosure affected you as a person? Have you been benefited from disclosure? Has disclosure opened the doors of opportunities for you?

RF: Disclosure has benefited me. Some people talk negatively about me and I would tell them off. Then that brings peace within me. I have told my boss is that I am sick so that they understand when I'm feeling sick or going to the hospital to collect medicine. When I go to collect medicine sometimes I find long queues. I have no problem with disclosure I can even go to the radio station and disclosed my status. But because of my position at I tend hold back.

I: So, disclosure has been beneficial to you?

RF: Yes, it's healing to me. I'll leave positively. I do not mind disclosing.

I: What form a healing? Physical or mental healing?

RF: Mental healing.

I: When you meet someone who is also HIV positive how do you feel?

RF: I will tell them to take me as an example and just go ahead and take the medicine. I usually tell them that is what is important is to be positive.

I: Do you feel connected and bonded because you're also HIV positive?

RF: Very much, I feel bad.

I: If today we brought someone who is negative and someone who is positive or with whom would you bond with?

RF: someone who is HIV positive.

I: Why is that?

RF: Because I am also HIV positive and I know how it feels.

I: When you say you feel for them, what exactly do you mean?

RF: Well maybe they don't have any food, they might not have anyone to take care of them, and no money. I am better off because the government is paying me and meeting some needs. But here is someone with HIV positive and they have nothing to eat. This medication causes us to have a good appetite someone needs to eat much.

I: How expensive has it been for you to maintain your health?

RF: It has been very expensive. But, I have to manage and eat according to what money I get. If I decide to buy something I can't afford, I will just get depressed because I can't.

I: What are your thoughts about the future as a teacher who is on ART?

RF: As a teacher I have been involved in building. When I came to this school there were just two buildings, I have built 3 classroom blocks and I've started another one. By the time I will be retiring in 2019, I hope I will leave the school in a good state so that my grandchildren and great grandchildren will be able to say our grandmother did a good job with the school and they will be proud. Actually, some of them are already at this school.

I: Do you sometimes attach your condition of being positive to some of the successes that you have recorded so far?

RF: yes. Some people think when they are dying because of being on ARVs but that is not the case. Some people would not want to do anything to progress. But for me to see this access I thank God that I was to alive and worked hard.

I: In terms of finances, relationships with people, what are your thoughts towards the future? That is in terms of making more money outside teaching and what are your thoughts concerning relationships in future?

RF: You mean socially?

I: Yes, like strengthening social networks.

RF: Yes. If there is someone who can help us, let them do so because, there are so many people I know who are sick. It is so easy to go through the community and identify people that are sick because I am the head teacher here and know many parents and their children. Some of the pupils who are HIV positive would run away from me, but I would talk to them and say “my daughter take the medicine I’m also sick, be yourself and take your medicine.” I have opened up to some girls and after that there is that bond. They are able to come to me and talk. If at all there is anything, those are the people I can attach to benefit.

I: Do you worry about physical pain in your future or do you worry about death?

RF: The physical pain is what will happen when I stop working? How am I going to take care of my home and feed my family? Pension does is not released early enough in our country and I ask myself if I will even get my money before I die. I usually tell my children that they have to take care of me. I have children that are working. I tell them that I need a good diet. Those are my future plans. I need to be comfortable for me to continue taking these drugs because I cannot take them on an empty stomach. I’m coming to the end of the journey when it comes to work.

I: So are you saying you worry about physical pain like tomorrow you might wake up to find your leg or arm swollen, do you worry about such things?

RF: I do not worry of such but the high blood pressure that I suffer from. I do not know whether it’s the drugs that cause my blood pressure to be abnormal and my eyesight is even affected. As a human being it is normal to worry about such things. My health is going lower and lower bit by bit and so it’s normal for me to get worry.

I: Do you sometimes worry about death?

RF: No, I don’t know. I can die even tomorrow, and I don’t worry because I have run my grace. I am a proud person.

I: Is there anything else you would like to say based on what we have talked about?

RF: My husband tells me that he is HIV free, but I am positive. This thing has affected our sex life. I’m talking to you as someone I can confide in. I told him that because he is HIV negative and I am positive he has to use a condom when we have sex. That is so he can live longer when I am gone and take care of our

children. I am a condemned person. I don't know where I contracted the virus from.

I: Has he gone for testing?

RF: Yes, he has he is a clinical officer although he is retired now.

I: Have you going for testing together?

RF: No, we have not gone together. He would go alone for the HIV test. I am on medication and he is not.

I: How long have you been married?

RF: I have been married for almost 38 years.

I: How long have you been teaching?

RF: I have been teaching for almost 34 years.

I: And how old are you?

RF: I am 56.

I: Is there a medical explanation as to why he is negative, and you are positive?

RF: I cannot understand.

I: Haven't you taken the initiative to find out from the doctors?

RF: No, I haven't, I have decided to just let it be.

I: Please remind me. How long have you lived a positive life?

RF: 7 years. I am not promiscuous or go around sleeping other woman's husbands, I keep myself holy but here I am in this predicament. At first, I used to grapple and complain about how I got the infection but this time around I have accepted the situation. I don't need to blame my partner. How do I blame him when he is HIV negative? So, I do not know where and how I got it.

I: Do you have medical confirmation of how free he is?

RF: No.

I: So, its through word of mouth?

RF: Yes.

I: How often do you talk about it with him?

RF: I do not even want to talk about it.

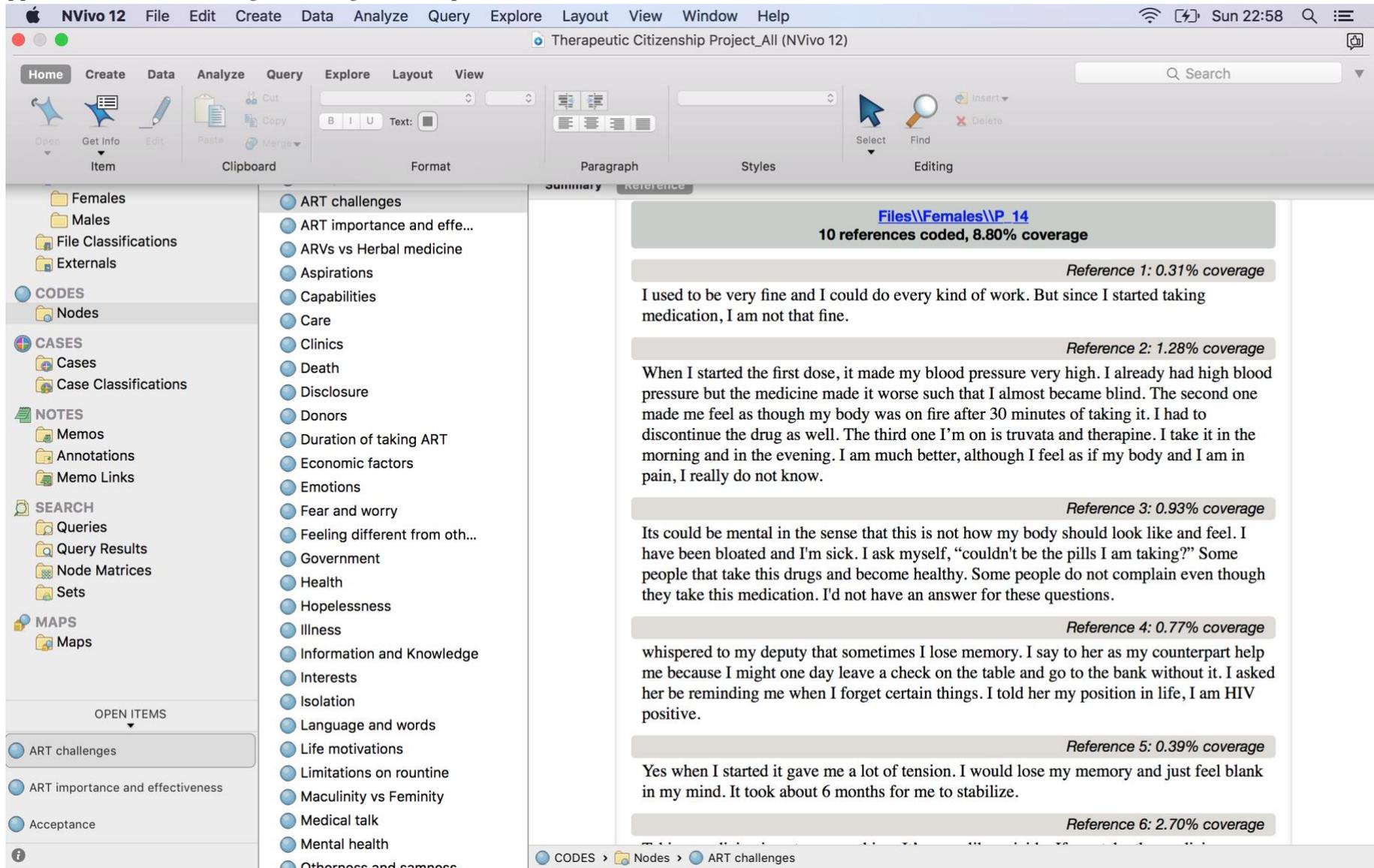
I: Okay. Anything else you would like to share with me based on what we have talked about?

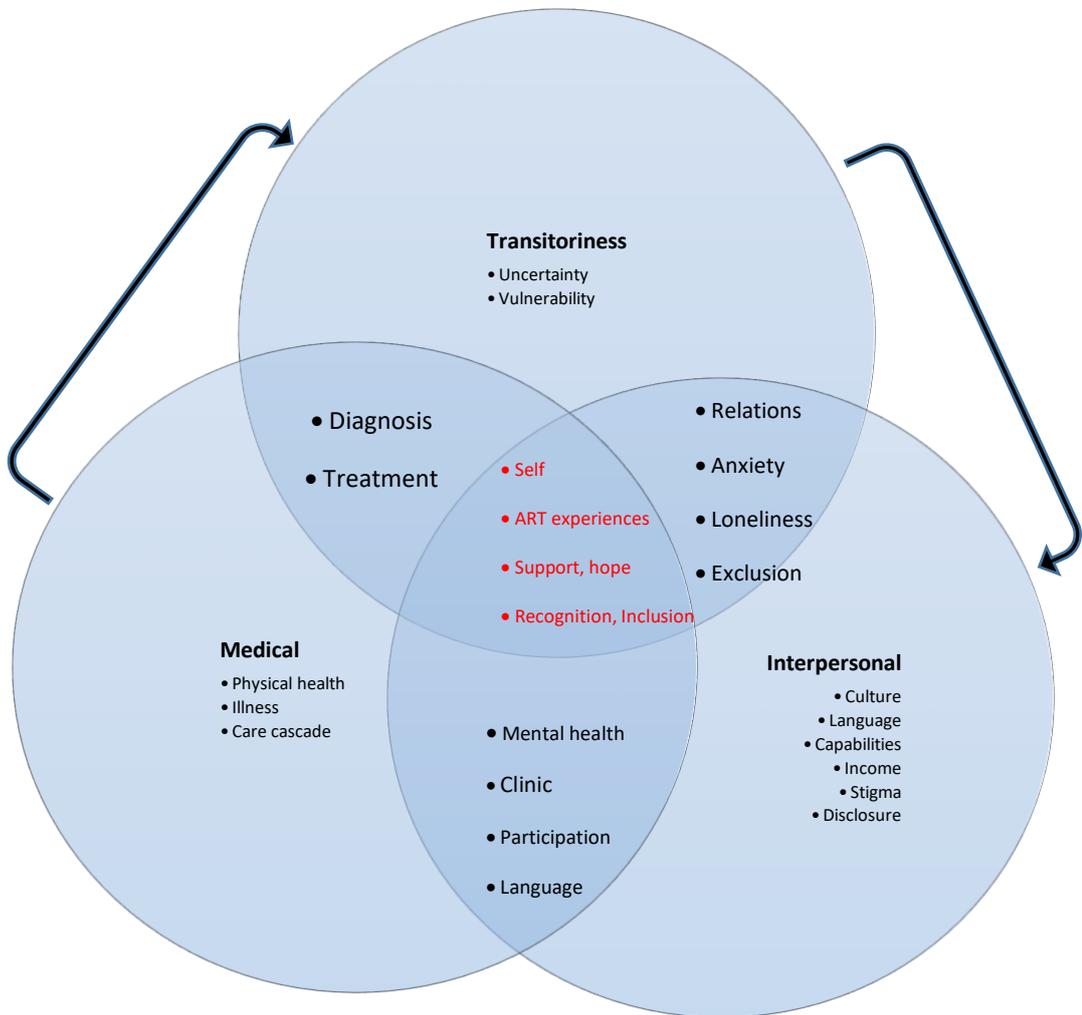
RF: There isn't much but if there is someone who can help, let them help us. It could be financially, or materially. If we need to form up some groups so that they can help us we can do that. That way we can help some people living with

HIV because some of them feel it is the end of the world. Some people die out of fear when they told that they are HIV positive. I thank you for coming.

I: Thank you very much for your time.

Appendix 11: NVivo coding and categorisation process





# CERTIFICATE of ACHIEVEMENT

This is to certify that

**SANNY MULUBALE**

has completed the course

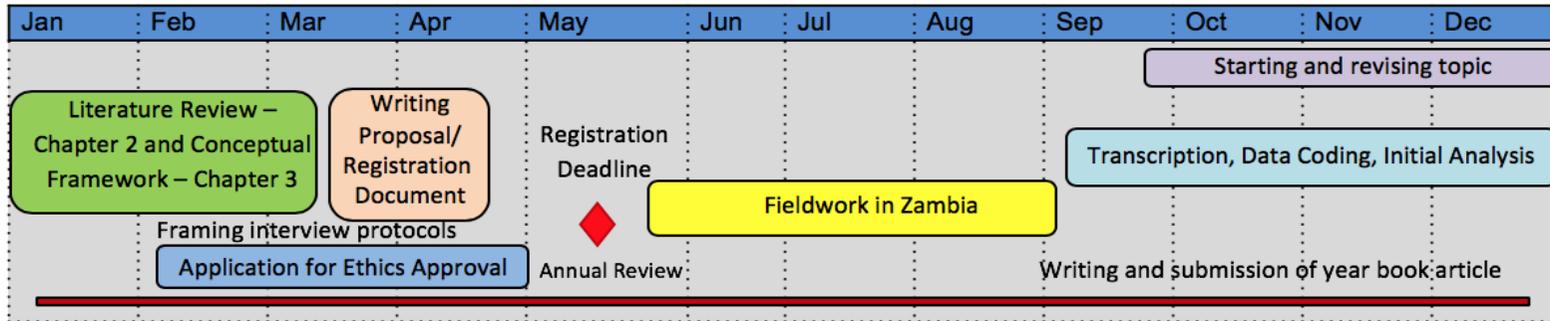
Research Integrity Modules

12 November 2016

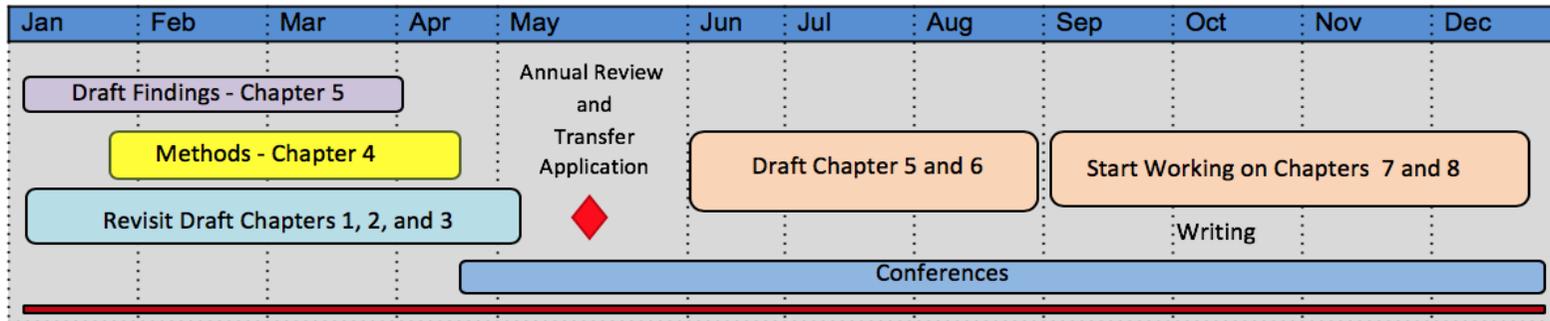
End of course quiz - Social and Behavioural Sciences Grade: 80.00 %

Appendix 13: Work plan for entire research and thesis

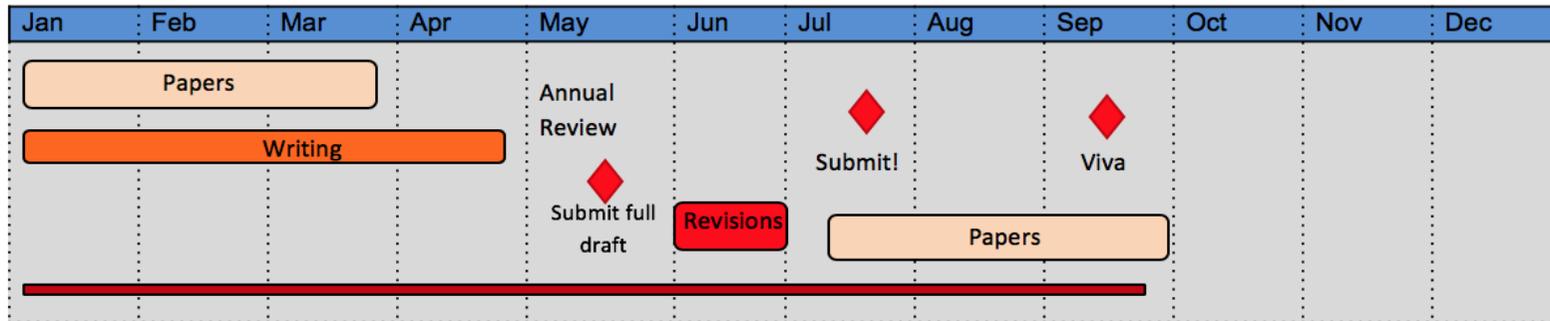
**Year 1 – September 2016/2017**



**Year 2 – 2018**



**Year 3 – 2019**



## Endnotes

<sup>i</sup> Some material from chapters one, two and three has been published in the University of East London's postgraduate yearbook, available at <https://core.ac.uk/download/pdf/161817045.pdf>.

<sup>ii</sup> This work on the body may have engaging implications for the consideration of HIV representations and concepts of bodies, but this is beyond the scope of this thesis, which does not explicitly address the body, conceptually or in terms of the data.