EXPLORING HOW THE MANAGEMENT OF HOUSEHOLD INCOMES IMPACT ON ANTIRETROVIRAL THERAPY ADHERENCE BEHAVIOUR OF PEOPLE LIVING WITH HIV IN THE WESTERN CAPE, SOUTH AFRICA.

By

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DISSERTATION PRESENTED IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF PHILOSOPHY IN TRANSDISCIPLINARY HEALTH AND DEVELOPMENT STUDIES AT STELLENBOSCH UNIVERSITY.

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Summary

The Human Immunodeficiency Virus (HIV) epidemic presents a global health crisis, with approximately 38 million people worldwide living with HIV (PLHIV) in 2019. Amongst them, an estimated 7.8 million PLHIV live in South Africa. In 2016, the South African government increased access to HIV testing and treatment following the proposed ‘universal test and treat’ strategy advocated by the World Health Organisation (WHO). However, there remains a significant treatment gap as only 4.8 million PLHIV are estimated to be receiving antiretroviral therapy (ART) in the country, and many of those on ART are experiencing challenges in adhering to treatment. Several studies have found that factors surrounding household income are contributing to these challenges. In this study, I explored how the management of household incomes impact the ART adherence behaviour of PLHIV from 13 families affected by HIV in the Western Cape of South Africa. I have drawn findings from the data collected as part of the HPTN 071 (PopART) trial, where in intervention communities, HIV care was delivered at a household level and HIV treatment was made available to all PLHIV prior to changes in the national HIV guidelines. I used Bronfenbrenner’s ecological framework, which entails characterising social life in five levels including the microsystem, mesosystem, exosystem, macrosystem, and chronosystem to interpret the results. Using a thematic approach to organise and analyse data, I first described how families ‘got by’ including social grants and social support; informal borrowing and loans; employment; and independent survival strategies. I found that families managed their procured incomes differently depending on varying household priorities. I found that there is fluidity on the ART adherence behaviours of PLHIV. People could iteratively move from being reluctant, to being adherent and interrupt treatment due to life changes. In the study, I found that factors in the immediate environment (micro-level), including competing household priorities, lack of resources, and recreational activities, have the strongest influence on ART adherence behaviours of PLHIV. I found that households have the potential to create a positive health-enabling environment for PLHIV through adjusting their expenditure patterns in a manner that facilitates optimal adherence to care. However, there were various determinants surrounding ART adherence that operated beyond the influences located at the household level. I propose that future health interventions should be increasingly tailored for household-specific needs, but should also be wary of neglecting factors associated with ART adherence existing beyond the household level.

Opsomming

Die Menslike Immuniteitsgebreksvirus (MIV)-epidemie skep 'n wêreldwye gesondheidskrisis, met ongeveer 38 miljoen mense wêreldwyd wat met MIV leef (PLHIV) in 2019. Na beraming woon 7,8 miljoen mense wat met MIV leef in Suid-Afrika. In 2016 het die Suid-Afrikaanse regering toegang tot MIV-toetsing en behandeling verbreed na aanleiding van die voorgestelde strategie vir 'universele toets en behandeling' wat deur die Wêreldgesondheidsorganisasie (WGO) voorgestaan word. Daar is egter 'n beduidende behandelingsgaping, aangesien slegs 4,8 miljoen PLHIV na verwagting antiretrovirale terapie (ART) in die land ontvang, en baie van diegene op ART ervaar uitdagings om behandelings riglyne na te kom. Verskeie studies het bevind dat faktore rondom huishoudelike inkomste tot hierdie uitdagings bydra. In hierdie studie ondersoek ek hoe die bestuur van huishoudelike inkomste die ART-nakomingsgedrag beïnvloed van PLHIV uit 13 gesinne wat deur MIV in die Wes-Kaap van Suid-Afrika geraak word. My bevindinge is gebaseer op data wat versamel is as deel van die HPTN 071 (PopART) -proef, waar MIV-sorg op huishoudelike vlak gelewer is in intervensiegemeenskappe en MIV-behandeling aan alle PLHIV beskikbaar gestel is voordat die nasionale MIV-riglyne verander is. Ek het die ekologiese raamwerk van Bronfenbrenner gebruik om my resultate te interpreteer. Volgens hierdie raamwerk word sosiale lewe op vyf vlakke beskryf insluitend die mikrosisteem, mesosisteem, eksosisteem, makrostelsel en chronestelsel. Met behulp van 'n tematiese benadering om data te organiseer en te ontleed, het ek eerstens beskryf hoe gesinne 'klaar kom', wat insluit maatskaplike toelaes en maatskaplike ondersteuning, informele lenings, indiensneming, en onafhanklike oorlewingstrategieë. Ek het bevind dat gesinne hul verkrygde inkomste anders bestuur, afhangende van die verskillende huishoudelike prioriteite. Ek het bevind dat daar n ‘vloeibaarheid’ in die ART nakoming is deur PLHIV. Mense beweeg tussen huiwering oor behandeling, tot getrou aan behandeling, tot onderbreekte behandeling, afhangend van lewensveranderinge. In die studie het ek gevind dat faktore in die onmiddellike omgewing (mikrovlak), waaronder kompeterende huishoudelike prioriteite, gebrek aan hulpbronne, en ontspanningsaktiwiteite, die grootste invloed het op PLHIV se nakomingsgedrag aan ART. Ek het bevind dat huishoudings die potensiaal het om 'n gesondheids-omgewing vir PLHIV te skep deur hul uitgawepatrone aan te pas op 'n manier wat optimale nakoming van sorg kan fasiliteer. Daar was egter verskillende faktore rondom ART-nakoming wat buite die invloed van huishoudelike vlak bedryf word. Ek stel voor dat toekomstige gesondheidsintervensies toenemend aangepas moet word vir huishoudingspesifieke behoeftes, maar ook moet waak teen die verwaarlosing van faktore wat verband hou met ART-nakoming wat buite die huishoudelike vlak bestaan.

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARVs	Antiretroviral(s)
DTTC	Desmond Tutu TB Centre is a research centre in the Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University
HIV	Human Immunodeficiency Virus
HPTN 071 (PopART)	HIV Prevention Trial Network 071 (Population Effects of Antiretroviral Therapy to Reduce HIV Transmission)
NDOH	National Department of Health
PrEP	Pre-exposure prophylaxis
PEP	Post-exposure prophylaxis
PMTCT	Prevention of mother-to-child transmission (of HIV)
PLHIV	People living with HIV
SANAC	South African National AIDS Council
UTT	Universal test and treat
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Research problem and background

The Human Immunodeficiency Virus (HIV) epidemic is a global health crisis. In 2019, an estimated 38 million people were living with HIV (PLHIV) (UNAIDS, 2019). Amongst them, approximately 36 million were adults and 1.8 million children between the ages of 0 – 14 years. In 2019 alone, there were an estimated 1.7 million people newly infected with HIV and 690 000 people were thought to have died from HIV-related illnesses (UNAIDS, 2019). The impact of HIV has been most severe in the African continent, and specifically so in the sub-Saharan region. Estimates show that of the 38 million PLHIV, 70% live in sub-Saharan Africa (UNAIDS, 2020). Within the sub-Saharan region, South Africa is reported to have the largest share of the HIV epidemic with approximately 7.7 million PLHIV in the country in 2018 (Simbayi, Zuma, Zungu, *et al.*, 2018).

In the South African context, HIV has had a severe effect on both the physical and financial well-being of the individuals, households, and communities affected by the disease (Bachmann & Booysen, 2003; Moosa, Gengiah, Lewis, *et al.*, 2019; Steinert, Cluver, Melendez-Torres, *et al.*, 2017). Left untreated, HIV has a devastating effect on one's body as it weakens the immune system which ultimately makes it harder for the body to fight off opportunistic infections (Moosa *et al.*, 2019). However, since the introduction of antiretroviral therapy (ART) in South Africa in 2004, the quality of life and life expectancy of PLHIV has dramatically improved and the country reported lower HIV related deaths over the years (Adam & Johnson, 2009; Shisana, Simbayi, Rehle, *et al.*, 2014).

At the broader socio-economic scale, the financial impact of HIV varies from the macro-economic level to the household level. At the macro-economic level, the impact of HIV is partly due to the high costs of treatment allocated by the government; which divert resources from economic productive investments (Haacker, 2004; Steinert *et al.*, 2017). At the household level, the effect of HIV is on household savings and labour productivity (Sharma, Krishnaswamy & Mulay, 2015; Steinert *et al.*, 2017). For instance, the care of and loss of family members living with HIV translates into losses of household income through higher medical expenses and funeral costs (Steinert *et al*, 2015).

HIV burden in households affected by HIV further results in changes in expenditure patterns and in turn, in private savings and investments (Booysen, Geldenhuys & Marinkov, 2003; Sharma *et al.*, 2015). It is reported that supporting the ART adherence of a relative means investing valuable time, energy and household financial resources into a single individual (Merten, Kenter, McKenzie, *et al.*, 2010). However, little is known about how the management of household incomes affect ART adherence, particularly in the context of 'universal test and treat' (UTT) where ART is widely available and accessible to all PLHIV (Lockman, Holme, Makhema, *et al.*, 2020; National Department of Health, 2016). In an attempt to address this gap, this study first offers an in-depth analysis on how families affected by HIV 'get by' including their expenditure patterns as a primary overlay to address the main research aim. I explore how the management of household incomes impact on ART adherence behaviour of PLHIV, more specifically, in the context of UTT. To begin with, below I describe the changes in HIV treatment guidelines over the years and their impact on the South African treatment landscape. Later, I briefly provide an overview of socio-economic factors affecting ART adherence which co-exist in the context of UTT.

1.2 HIV treatment landscape in South Africa

Since the roll out of HIV treatment in South Africa in 2004, access to treatment has expanded exponentially over the years. The national treatment guidelines developed over time and the eligibility of access to HIV treatment improved (NDOH, 2016). Public health expects stipulated that increased access and the wider availability of treatment might end the epidemic, but it depends on the ART adherence behaviour of PLHIV (Granich, Gilks, Dye, *et al.*, 2009; Hayes, Sabapathy & Fidler, 2011).

Early modelling of universal voluntary counselling and testing followed by immediate initiation of ART for all those diagnosed HIV-positive was anticipated as a potential means to reduce HIV incidence dramatically if PLHIV were to be virally suppressed (Granich *et al.*, 2009). Viral suppression is defined as literally suppressing or reducing the function and replication of a virus (Lazarus, Safreed-Harmon, Barton, *et al.*, 2016). Viral suppression is usually achieved when ≥ 95 % of tablets are taken by PLHIV (Moosa *et al.*, 2019). It is also proposed that the early initiation of ART will significantly reduce deaths attribute to HIV related illnesses as well as vertical and horizontal transmissions (Moosa *et al.*, 2019). The ground-breaking HPTN 052 study found that when PLHIV are on ART and virally suppressed, then they are unlikely to transmit the virus to their sexual partners (Cohen, Mccauley & Gamble, 2011). Based on this evidence, several community-based trials, including the HPTN 071 (PopART) trial in South Africa and Zambia, were implemented to evaluate the effects of widespread HIV testing and earlier access to HIV treatment at a population level (Hayes, Ayles, Beyers, *et al.*, 2014; Perriat, Balzer, Hayes, *et al.*, 2018).

In 2015, the World Health Organisation (WHO) proposed universal HIV testing and increased access to treatment (UTT) as part of their strategy to curb the HIV epidemic. The rationale behind UTT is to maximize the proportion of people living with HIV who receive ART and to achieve a wider viral suppression amongst PLHIV (WHO, 2015a). This new prevention strategy states that every individual living with HIV is eligible to initiate ART, regardless of their CD4 count (WHO, 2015a). In 2016, the South African National Department of Health (NDOH) implemented these guidelines in the country (Meyer-Rath, Johnson, Pillay, *et al.*, 2017). Currently, South Africa has the largest running ART programme in the world and ART services have undergone dramatic expansion in recent years (UNAIDS, 2019).

Despite the efforts to curb the epidemic through UTT implementation, in 2018, there remained a significant treatment gap with only 4.8 million PLHIV (out of 7.7 million PLHIV) estimated to be receiving ART in South Africa (Simbayi *et al.*, 2018; UNAIDS, 2019). The burden of HIV disease continues to grow in the country although mathematical models predicted that a public health approach of UTT has the potential to dramatically reduce HIV incidence (Granich *et al.*, 2009; Hayes, Donnell, Floyd, *et al.*, 2019).

A variety of factors have been identified that impede ART adherence, even in the context of expanded access to HIV treatment. The literature has revealed that, in Southern Africa, socio-economic aspects such as unemployment, poverty, food insecurity, and HIV treatment-related costs are related to poor ART adherence (Azia, Mukumbang & Van Wyk, 2016; Kibret, 2018; Seeley, Bond, Yang, *et al.*, 2019; Weiser, Tuller, Frongillo, *et al.*, 2018). Social factors, such as stigma and discrimination, non-disclosure and lack of social support have also been identified as impeding ART adherence (Hargreaves, Stangl, Bond, *et al.*, 2016; Treves-Kagan, Steward, Ntswane, *et al.*, 2016; de Villiers, Thomas, Jivan, *et al.*, 2020). Individual factors such as forgetfulness, the experienced and anticipated side effects of ingesting ART, “feeling better”, and mistrust of and myths surrounding ART form part of the documented factors that potentially hinder many patients from adhering to treatment (Seeley *et al.*, 2019; Siefried, Mao, Kerr, *et al.*, 2017). Studies have also shown that household income constitute as one of many delaying factors of effective ART adherence in South Africa, even when treatment access is expanded (Campbell, Masquillier, Thunnissen, *et al.*, 2020; Hoddinott, Myburgh, de Villiers, *et al.*, 2018; Steinert *et al.*, 2017).

The impact of household income on ART adherence interacts with factors such as inadequate resources, employment responsibilities versus time to access care, and competing priorities within a household (Masquillier, Wouters, Mortelmans, *et al.*, 2016; Seeley *et al.*, 2019; Steinert *et al.*, 2017). For instance, the time spent travelling to and attending clinical appointments places economic strain on patients and their families by competing with income-generating activities (Azia *et al.*, 2016; Steinert *et al.*, 2017). Studies in southern Africa show that PLHIV often have to balance attending health care services and/or going to work, both which are deemed to be important to the well-being and survival of PLHIV and their households (Seeley *et al.*, 2019; Steinert *et al.*, 2017). It has also been found that PLHIV who were the main breadwinners and had not started ART, would rather use their strength to earn an income and continue providing for their families while they were feeling healthy, than go for treatment (Seeley *et al.*, 2019; Steinert *et al.*, 2017).

In some cases, particularly in resource constrained settings where incomes are limited, PLHIV reported that they struggle to adhere to ART due to inadequate resources such as food or additional medication to counter side-effects when on ART (Becker, 2019; Siefried *et al.*, 2017). This means inadequate food access poses additional challenges to the success of ART adherence in addition to the lack of financial security (Young, Wheeler, McCoy, *et al.*, 2014a). Besides household income, other factors within the household such as interpersonal relationships with partners or family members can also influence the decisions to seek HIV testing, engage in care, and stay in care (Masqullier *et al.*, 2016; Seeley *et al.*, 2018; Dlamini-Simelane & Moyer, 2017). Lack of support from family and friends has been found to be a significant factor for delaying PLHIV from initiating their ART medication (Ahmed, Autrey, Katz, *et al.*, 2018).

However, as treatment for all and wider delivery of HIV treatment is now standard in South Africa, it means that more people are eligible to access treatment but the socioeconomic challenges remain mostly unchanged. Although a myriad of challenges have been widely documented in the literature (see above), we still do not know how treatment access for all will be affected by economic factors in households, including how incomes are managed. In this study, I aim to describe how the management of household incomes affect ART adherence of PLHIV.

1.3 Research context and rational

As explained above, one effective way to curb the HIV epidemic is by taking ART to ensure viral suppression (Granich *et al.*, 2011; Hayes *et al.*, 2011). One way to ensure that everyone is able to access ART is through the strategy of UTT. This strategy was tested in the HPTN 071 (PopART) trial which was implemented in Zambia and in the Western Cape province of South Africa. The PopART study aimed to examine the impact of a package of HIV prevention interventions on community-level HIV incidence (Hayes *et al.*, 2014). The PopART trial was a three armed randomized control study where intervention communities received door-to-door HIV testing and prevention services and the control communities received standard of care (Hayes *et al.,* 2014). The prevention interventions included universal voluntary HIV counselling and testing at household level, linkage to care for people who tested positive for HIV, and early initiation of ART for all those testing HIV-positive in some communities, prior to the changes in national HIV treatment guidelines (Hayes *et al.*, 2014).

In South Africa, the PopART study was implemented in 9 communities in the Western Cape. The Western Cape previously recorded the lowest prevalence of PLHIV in the country, sitting at 5 % in 2012 (Shisana *et al.*, 2014). However, in 2017 the Western Cape province accounted for 8.9 %, showing a worrying increase of 3.9 % from 2012, also recording the highest number of new infections compared to other provinces within the time frame between 2012 - 2017 (Simbayi *et al.*, 2018). My study focuses on the 6 PopART intervention communities located in the Western Cape province of South Africa.

The PopART study presented the opportunity to understand treatment experiences of PLHIV at the household and community population level. In this study, I draw on qualitative data from the PopART study to understand the impact that the management of household incomes have towards ART linkage and care behaviour of PLHIV in the Western Cape. The management of household incomes include how families affected by HIV negotiated their incomes, expenses, and living costs, as well as household priorities. This includes exploring family income sources and expenditure, as well as trying to understand how the availability (or lack of) income influences people's ability and willingness to engage with the health care system. In understanding how incomes are managed, I was able to gauge where health and care fit into daily family expenses and the lens through which I can view what the direct and indirect costs associated with HIV, ART and care are. With that in place, I was also able to determine where ART and treatment fit into household priorities and understand what potential barriers to treatment entail.

I used the lens of Bronfenbrenner's Ecological Framework for Human Development (1979) for the analysis. According to this framework, the complex interactions and relationships between individuals and their multiple social and physical surroundings shapes their development (see Chapter 2 for detailed description). In this study, I applied this theory to understand health behaviours of PLHIV towards ART adherence.

In the following section I present the research aim and objectives of this study followed by the description of the study key concepts including: ART adherence, "getting by" and the management of household incomes. Thereafter, I provide an overview of the remaining chapters.

1.4 Research aim and objectives

The aim of this study is to explore how the management of household incomes affect antiretroviral therapy adherence of people living with HIV in the Western Cape province of South Africa, in the context of expanded access to HIV testing and treatment.

In order to address this research aim, I have the following objectives:

(i) To describe patterns in which households affected by HIV ‘get by’.
(ii) To thematically organize how incomes are managed by households affected by HIV.
(iii) To provide a thematic representation on how the management of household incomes affect ART adherence of PLHIV.

1.5 Key concepts

1.5.1 ART adherence

Since ART became widely available to PLHIV, health providers have been concerned with patients’ adherence to their medication. Health workers have been found to want to ensure the physical well-being of a patient but fear the impact of drug-resistance for patients who do not follow prescriptions (Meintjes, Kerkhoff, Burton, *et al.*, 2015). Health practitioners understand ART adherence as the ability of patients to follow treatment plans, take medications at prescribed times and frequencies and also follow restrictions and guidelines regarding lifestyles, food, and other medications (Azia *et al.*, 2016; Meintjes *et al.*, 2015; Reda & Biadgilign, 2012). Previously, there were challenges in reaching consensus on the definition of ART adherence between different researchers. The use of different methods of measuring adherence in clinical trials prevented a practical quantification of this concept or effective correction methods (Horne, 1999). These difficulties led to a multitude of confusing terminologies in both the scientific papers and in clinical practice.

More than a decade ago, the term “adherence” was used interchangeably with the term “compliance”. This occurred because they described the same behaviour, yet implied different motivations for it (Azia *et al.*, 2016). “Compliance” typically refers to the extent to which a patient obeys the advice and directive of a doctor and that patient behaviour should be measured in accordance with these orders (Siefried *et al.*, 2017). “Adherence” alternatively suggests a more concerted relationship between a provider and a patient, and it promotes a more collaborative study of variables that affect adherence (e.g., regimen, context etc.) (Ford, Calmy & Mills, 2011; Nagata, Magerenge, Young, *et al.*, 2012). For the purpose of this study, ART adherence refers to keeping appointments with health care providers, refilling prescriptions, correctly counting the medications to be taken, and ensuring that medications are taken at the right time of day and in accordance with dietary guidelines(Azia *et al.*, 2016; Moosa *et al.*, 2019; Nagata *et al.*, 2012).

However, achieving ART adherence is complicated with multiple factors that are part of the process of taking ART, including using additional medication to manage side-effects of ART, balance between ART and work, ingesting appropriate food before taking pills, and transport costs to the clinic, amongst other things (Reda & Biadgilign, 2012; Steinert *et al.*, 2017; Young *et al.*, 2014a). These factors are also considered in the description of ART adherence in this study.

1.5.2 ‘Getting by’

Prior to defining ‘getting by’, it is important to first understand what is meant by household income. Household income is any resource earning, whether regular or irregular, cash (money, funds) or non-cash (food, assets, goods) which can be consumed or spent immediately (Romich, 2009; Smeeding & Weinberg, 2001). Central to this study is understanding the ways in which households affected by HIV secure incomes and how they survive in terms of finances and resources. The means to survival or ways to generate income is grouped as ‘getting by’. During qualitative data collection in the HPTN 071 (PopART) study in which this project is nested (see chapter 3), the term 'getting by' was used to describe the various ways in which households generate income, resources, and other means in order to ensure survival. 'Getting by' was also used to describe how decisions are made about spending income and household resources during the PopART study. For the purpose of this study, I define 'getting by' as ways in which household secure the means to survive including, amongst other things, borrowing money, through employment, running a business, illicit activities, selling assets, exchanging resources, receiving food parcels, and gifts(Kibret, 2018; Naidu & Harris, 2005; Smeeding & Weinberg, 2001).

1.5.3 The management of household incomes

We also cannot understand what is meant by the concept 'management of household incomes', without describing the term 'household' first. The household refers to members, related or unrelated, who share the same dwelling unit or housing structure (Smeeding & Weinberg, 2001). In this study, the process in which all attained resources including funds, food, assets, and/or goods (as noted in the section above) are organised, negotiated, prioritised, and spent is referred to as the management of household income. The management of household incomes further entails how families decide on their incomes and expenses, including how some expenses are prioritised over others (also see Maslow, 1943; Lester, Hvezda, Sullivan, *et al.*, 1983). Exploring how households manage their incomes enabled me to gauge where health and health care fit into daily family expenses and provided a lens through which I can view what the direct and indirect costs associated with HIV, ART, and care is.

1.6 Overview of Chapters

In the following chapter, I describe HIV response and prevention programmes implemented by the South African government to address the epidemic, including the challenges faced by these implementation programmes. I then provide the bilateral relationship between household income and ART adherence. Following, I discuss other factors affecting ART adherence and the ART adherence experiences of PLHIV in South Africa. I introduce Bronfenbrenner's Ecological Framework for Human Development (1979) and its five components namely the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem. I show how these components are interconnected and the importance of using this theory in my study.

In Chapter 3, I expand on the methods undertaken in the study. First, I describe the research design. Then, I provide a detailed description of the HPTN 071 (PopART) trial, which my project is embedded in. I also describe the study setting and my study sample. Thereafter, I expand on the data collection process, analysis, and provided details on the trustworthiness of the study. Lastly, I give a description of ethical procedures and considerations undertaken by the study and reflected on my position in the study.

In Chapter 4, I present the key findings from the 13 selected families affected by HIV in my dataset. I describe patterns in which families 'get by' and I thematically organised how they managed their incomes. Lastly, I provide a thematic presentation on how the management of incomes impact on ART adherence of PLIHV.

In Chapter 5, I use the lens of Bronfenbrenner's theory to contextualise and interpret my findings. I also reflect on how the existing literature on household income and ART adherence support or contradict my findings. Additionally, I discuss the strengths and limitations of my study and the impact it may have had on my findings. Lastly, I provide recommendations for future studies and present concluding thoughts on the study.

Chapter 2: Literature review

In this chapter, I describe the HIV response and prevention methods that the government of South Africa has put in place to curb the epidemic, including the challenges faced by these programmes. I provide literature on the bilateral relationship between household income and ART adherence. Thereafter, I provide an overview of factors affecting adherence along with the disciption of ART adherence experiences of PLHIV in South Africa. Following, I provide the theoretical framework used in this study; Bronfenbrenner's Ecological Framework for Human Development (1979) and discuss its five interrelated components, namely the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. Lastly, I explain the importance of using this theory in my study.

2.1 HIV response in South Africa

In response to address and curb the HIV epidemic in the country, the South African government has put in place a number of HIV prevention strategies over time. The prevention strategies include, among other initiatives, the National HIV testing and counselling (HTC) campaign in 2010, the widespread distribution of condoms, voluntary medical male circumcision (VMMC), and multiple HIV awareness and educational programmes (Barnabas, van Rooyen, Tumwesigye, *et al.*, 2016; Department of Health Republic South Africa, 2015; Simelela & Venter, 2014; South African National AIDS Council, 2017).

The national HIV testing and counselling campaign was meant to reduce HIV infection through increasing the scale of HIV testing beyond the health care facilities to testing at community level (SANAC, 2015). Early testing, accompanied by initiation and continuous access to treatment, has been documented to have numerous benefits including reducing HIV transmission in both men and women, earlier viral load suppression, and may instil safe sexual behaviour (Cohen *et al.*, 2011; Hansoti, Mwinnyaa, Hahn, *et al.*, 2019; Hayes *et al.*, 2011). Those who have taken an HIV test and know their status are more likely to have been found having higher levels of education about HIV and higher perception of risks (Mampane, 2018; Viljoen, Ndubani, Bond, *et al.*, 2017). Another prevention strategy deployed by the South African government was the scaling of condom use and distribution. In the National Strategic Plan (NSP) in 2017, the South African National AIDS Council aimed to increase the number of male condoms distributed annually to 850 million by 2018. South Africa's female condom programme is also one of the biggest and most established in the world, with over 26 million female condoms distributed in 2016 (NDOH, 2017). However, challenges remained in ensuring that condom programmes are able to serve all groups, particularly those with higher HIV risk exposure (Viljoen *et al.*, 2017).

In 2010, a research emerged from sub-Saharan Africa suggesting that voluntary medical male circumcision can reduce the risk of female-to-male HIV transmission by up to 60 % (Barnabas *et al.*, 2016). This led the South African government to rapidly roll out the national VMMC programme, which aimed to reach 80% of HIV negative men by 2016 (NDOH, 2017). However, these targets were met with challenges. In 2017, around 32 % of adult men (aged 15 – 64) were estimated to have been medically circumcised (Avert, 2019). Despite being off-target, South Africa is continuing to increase the number of medical circumcisions.

In addition to these prevention strategies, a number of HIV awareness campaigns are in place in South Africa as means to educate people and most notably, the youth, about HIV. This includes campaigns such as the LoveLife campaign which promoted 'abstinence, be faithful and condomise' in the early years of HIV epidemic; the Soul City institute that promotes HIV education through TV and radio edutainment programmes; and MTV Shuga, a mass-media behaviour-change campaign that aims to improve the sexual and reproductive health of young people (Avert, 2019; Heathista, 2017; Institute, 2019; LoveLife, 2018).

The most recent addition to HIV transmission prevention methods is the use of treatment as prevention. The evolving treatment landscape, described in the sections below, was instrumental to the development of these treatment-based prevention modalities. This includes the Prevention of Mother to Child Transmission (PMTCT) programmes established in 2010, the Post Exposure Prophylaxis (PEP) and the implementation of Pre-Exposure Prophylaxis (PrEP) for some population groups in 2015 (Adeniyi, Ajayi, Ter Goon, *et al.*, 2018; Global Advocacy for HIV (AVAC), 2017; Simelela & Venter, 2014; SANAC, 2015).

According to SANAC (2017), women in South Africa are more likely to test for HIV when compared men. This is partly because antenatal services allow programmes that enable women to access HIV testing services during routine antenatal appointments (SANAC, 2017). Women further have more access and exposure to treatment through PMTCT programmes. Over the past decade, South Africa has made great progress in reducing mother to child transmission of HIV, largely due to the improvements in the choice of ART medication and the widespread accessibility of PMTCT programmes (Adeniyi *et al.*, 2018; NDOH, 2015). PMTCT offers a range of services for women to maintain their health and stop their infants from acquiring HIV. It is projected that around 1.4 million HIV infections among children would have been prevented between 2010 and 2018 due to PMTCT programmes (Adeniyi *et al.*, 2018)..

Following PTMTC, South Africa introduced post-exposure prophylaxis (PEP), a short-term ART treatment that reduce the likelihood of HIV infection after the exposure to the virus (SANAC, 2017). PEP requires a person who is HIV negative to initiate HIV treatment within a course of 72 hours after exposure and take ART for a period of 28 days (Moorhouse, 2015; SANAC, 2014). PEP is particularly beneficial to people who have been sexually assaulted or raped, people who have been exposed to blood through needle or accident at work, and people who have been exposed to HIV through consensual sexual contact (Moorhouse, 2015). The aim of PEP is to allow a person's immune system a chance to provide protection against the virus and to prevent HIV from becoming established in one's body (Moorhouse, 2015).

In December 2015, South Africa also became the first country in the sub-Saharan region to fully approve PrEP (PrEP Watch, 2017). Evidence shows that, when taken consistently and correctly, PrEP reduces the chances of HIV infection to near-zero (NDOH, 2020; PrEP Watch, 2017). In 2019, it was estimated that between 23 000 and 24 000 people were using PrEP in on-going and planned projects across South Africa (PrEP Watch, 2019). In 2015, an initial trial of PrEP was conducted amongst South African women. Results showed 76 % approval among the trial population and these results paved a way for a wider implementation of PreP (PrEP Watch, 2017).

In addition to these instrumental prevention strategies, recently there has been a tremendous development of Treatment as Prevention (TasP) implemented as means for PLHIV to suppress their viral count and prevent HIV transmission (Iwuji, Orne-Gliemann, Tanser, *et al.*, 2013; Orne-Gliemann, Larmarange, Boyer, *et al.*, 2015; Tanser, Kim, Vandormael, *et al.*, 2020). TasP typically refers to HIV prevention methods and programmes that use ART to decrease the risk of HIV transmission (Cohen *et al.*, 2011). This strategy can be employed at the community level through 'universal test and treat' and has been done in trial settings in South Africa (Hayes *et al.*, 2019; Iwuji, Orne-Gliemann, Larmarange, *et al.*, 2016; Perriat *et al.*, 2018). The HPTN 071 (PopART) study is the largest ever HIV 'test and treat' trial and involved around one million people in South Africa and Zambia between 2013 and 2018 (Hayes *et al.*, 2019). Results of the study found new HIV infections were 20% lower in communities where 'test and treat' was introduced alongside other prevention measures compared to communities that received standard of care (Hayes *et al*, 2019).

Another project, ANRS 12249 which took place in rural areas of KwaZulu-Natal province of South Africa, was one of the first five large-scale randomised trials looking at the benefits of a universal test and treat for public health, rather than for the individual or their partners (Iwuji, Orne-Gliemann, Larmarange, *et al.*, 2018; Perriat *et al.*, 2018). Despite increased access to HIV testing and getting people who were on treatment virally suppressed by the study, the results were disappointing; showing that those diagnosed often did not link to medical care, or took many months to do so (Orne-Gliemann *et al.*, 2015; Perriat *et al.*, 2018). Nevertheless, most evidence for the effectiveness of TasP has led to new 'test and treat' or 'treat-all' strategy – increasing testing and treatment coverage by initiating all people diagnosed with HIV to start ART immediately regardless of their CD4 count or viral load (WHO, 2015a). The rationale behind the universal 'test and treat' is to maximise the proportion of people living HIV who receive ART and to achieve a wider viral suppression amongst PLHIV (WHO, 2015).

The effectiveness of ART as prevention tool is backed by strong evidence and it is being used as a public health intervention as well as a patient-specific strategy (Shanaube & Bock, 2015; Shanaube, Schaap, Hoddinott, *et al.*, 2021). In September 2016, universal treatment for all PLHIV was incorporated into the South African national ART guidelines. The country's government-funded national ART programme is the largest globally, providing HIV care and ART to over 4 million people (NDOH, 2016; Simbayi *et al.*, 2018)

The UTT strategy directly supports 90-90-90 targets of ensuring that 90% of all PLHIV know their HIV status; 90 % of people with diagnosed HIV infection receive sustained ART and 90% of all people receiving ART have viral suppression (UNAIDS, 2014). The 90-90-90 strategy has since been updated to 95-95-95 (UNAIDS, 2020). It has been found that the introduction of ART medication has significantly reduced deaths attribute to HIV/AIDS as well as vertical and horizontal transmissions, especially in South Africa (Moosa *et al.*, 2019). Early clinical trials showed that patients that started treatment immediately after HIV diagnosis had lower rates of AIDS-related adverse events and improved viral suppression rates with no difference in post-initiation attrition rates, compared to patients who deferred ART (Cohen *et al.*, 2011; Granich, Kahn, Bennett, *et al.*, 2012; Perriat *et al.*, 2018).

Previously, when the national ART programme in South Africa was first launched in April 2004, patients were considered eligible for ART if they had a stage 4 illness or a CD4 count <200 cells (Adam & Johnson, 2009; Coetzee, Hildebrand, Boulle, *et al.*, 2004). Prior to that, demonstration projects had provided ART to PLHIV with advanced disease through government health services (Coetzee *et al.*, 2004). Several projects were located in the Western Cape province and the first project began in Khayelitsha in May 2001, followed by the project in Gugulethu in September 2002 (Coetzee *et al.*, 2004). The unavailability of an accredited clinic became the most salient barrier to access ART between 2004 and 2008 and, at the time, the treatment coverage rates were below 40% for eligible patients (Adam & Johnson, 2009). There were political events that contributed to this crisis. In South Africa, HIV denialism had a significant impact on public health policy from 1999 to 2008, during the presidency of Thabo Mbeki (McLaren, 2015; Simelela & Venter, 2014). The former president criticized the scientific consensus that HIV causes AIDS, beginning shortly after his election to the presidency (Simelela & Venter, 2014). This is believed to have had a huge impact on the spiked cases of HIV in South Africa. With long queues at most facilities, many died waiting to be enrolled on treatment (McLaren, 2015).

Prompted by periodic revisions to World Health Organisation's guidance on ART in the period between 2009 and 2016, the South African National Department of Health considered a range of changes to eligibility, drug regimens and programmatic features. Table 1 below shows these changes in HIV treatment guidelines between 2010 – 2016 in South Africa.

Table 1: *Timeline showing changes in South African HIV treatment guidelines between 2010 – 2016.*

Date	**Mandated changes in HIV treatment guidelines over time**
April 2010	- Adults: Eligibility at 350 CD4 cells/µl for patients with TB and pregnant patients; at 200 CD4 cells/µl for everyone else Children: Early paediatric treatment (≤ 1 yr)
Aug 2011	- Eligibility at 350 CD4 cells for all patients
Jan 2015	- Adults: eligibility at 500 CD4 cells universal treatment for patients with HBV or TB and those who are pregnant breastfeeding or within one year post-partum - Children: Early paediatric treatment (≤ 6 years)
Sept 2016	- Universal treatment for everyone

Source: (National Department of Health, 2016: 2)

Today, the dramatic increase and scaling up of HIV treatment means that the South African government distributes HIV treatment to more than 60 % of PLHIV (UNAIDS, 2019). The increased availability of ART essentially improved the survival rates through lowering incidence of opportunistic infections (Hansoti *et al.*, 2019). However, the development and improvement of HIV treatment in South Africa cannot be understood without citing the role played by civil societies towards changes in the HIV treatment guidelines. Civil society movements have been vital in placing HIV high up on the public health agenda and in finding solutions to challenging problems (Avert, 2019; Simelela & Venter, 2014). South Africa's treatment access movements led street protests and community activism with court challenges and high-level lobbying (Simelela & Venter, 2014). One of the most visible civil societies is the Treatment Action Campaign (TAC), formed in 1998 (Avert, 2019). The TAC has been a driving force in the South African HIV response, promoting access to HIV treatment and care for all South Africans – their first major success came in 2002, with the Constitutional Court ruling that South African government must provide ARV's to prevent mother-to-child-transmission (Simelela & Venter, 2014; TAC, 2018).

In addition, the community-based approaches to HIV services also played a role in improving retention to care. For example, a study in South Africa examined the success of community adherence clubs consisting of between 25 -30 people, which were led by community health workers and supported by nurses (Bango, Ashmore, Wilkinson, *et al.*, 2016). Clubs would meet every two months for group counselling, brief symptoms screening, and distribution of pre-packed ART (Bango *et al.*, 2016). The study found that the clubs resulted in 94% of those taking part in the study adhering to treatment after a year. Adherence clubs form part of many programmes that supports TasP at the community level in South Africa (Bango *et al.*, 2016).

Among the supporting efforts towards adherence to ART, the South African government also offered a relief package in the form of a disability grant as a means to support PLHIV depending(South African Social Security Agency, 2020). In South Africa, when HIV of patients progressed to Acquired Immune Deficiency Syndrome (AIDS), individuals would be eligible for the disability grant, and patients are entitled to a state funded monthly income of R1,860 for 6 months because of their illness-related incapacity to work (SASSA, 2020).

Widespread unemployment has meant that disability grants are an important, and at times, the only source of income until patients are well enough to work (Kagee, Remien, Berkman, *et al.*, 2011; Steinert *et al.*, 2017). Some researchers have found that, when disability grants are tied to AIDS-related indicators, such as CD4 count or viral load, non-adherence may potentially become an attractive option for patients who fear losing their grant if their CD4 count were to increase (Azia *et al.*, 2016; Steinert *et al.*, 2017). This is one of many problems faced by PLHIV and South African government in their effort to ensure optimal adherence to HIV care. In the next section, I expand on the challenges faced by ART programmes in South Africa.

2.2 Challenges faced by ART programmes in South Africa

The treatment as prevention strategy is dependent upon people adhering to their treatment. It is widely agreed that once treatment is initiated it should not be interrupted in order for it to be effective (Moosa *et al.*, 2019). ART programmes and their implementation in South Africa is encouraging but the salient challenges weakening its effectiveness remain intact (Nansseu & Bigna, 2017; Skhosana, Reddy, Reddy, *et al.*, 2016; Tanser *et al.*, 2020). The challenges facing ART programmes in South Africa include the inability to initiate and retain PLHIV on their treatment regimens despite wider availability and increased access of treatment (Ahmed *et al.*, 2018; Treves-Kagan *et al.*, 2016).

As anticipated by Hayes *et al.*, (2011: 1), “achieving high coverage of ART in resource poor-settings will become increasingly difficult unless HIV incidence can be reduced substantially”. Universal voluntary counselling and testing followed by immediate initiation of ART for all those diagnosed HIV-positive has the potential to reduce HIV incidence dramatically but would be very challenging and costly to deliver in the short term (Hayes *et al.*, 2011). Early modelling work of UTT implementation has been criticised for making unduly optimistic assumptions about the uptake and coverage of interventions (Shanaube & Bock, 2015).

Initially, many public health specialists were concerned that the dramatic expansion-scale of ART would overstretch clinics and services and reduce the quality of care (Moosa *et al.*, 2019). Indeed, it became evident after the implementation of UTT that health facilities in high burden settings, such as South Africa, had struggles with the increased patient burden, which potentially reduced the quality of care provided to new and existing patients (Moosa *et al.*, 2019; Onoya, Sineke, Hendrickson, *et al.*, 2020; Treves-Kagan *et al.*, 2016). Challenges of UTT implementation included clinic staff shortages and long waiting times to receive care at the clinic in the public health sector (Ahmed *et al.*, 2018; Onoya *et al.*, 2020).

There are also issues of patient acceptance of same-day ART, ART refusal, early patient disengagement from care, and intermittent adherence after starting ART (Ahmed *et al.*, 2018; Moosa *et al.*, 2019). Receiving ART immediately after diagnosis became challenging for PLHIV who did not feel sick and those who did not see HIV care as a priority at the time (Ahmed *et al.*, 2018). Others needed time to accept and disclose their HIV status before they become ready to engage in HIV care and treatment for life. Hence, a study by Plazy *et al.*, (2017) on health care worker's experiences about UTT underlined the importance of not forcing people high CD4 count to initiate ART immediately in order to avoid treatment interruptions.

Researchers have also found that the ART programmes in South Africa do not adequately address the issue of poverty among PLHIV (Azia *et al.*, 2016; Bigna, Plottel & Koulla-Shiro, 2016; Mudzengi, Sweeney, Hippner, *et al.*, 2017). Poverty is highly correlated with food insecurity which is known to affect ART adherence in multiple ways, despite wider distribution of ART in the country (Nansseu & Bigna, 2017; Young *et al.*, 2014a). Other factors delaying the effectiveness of UTT in South Africa include anticipated stigma, lack of privacy in health facilities, and substance use (Hargreaves, Krishnaratne, Mathema, *et al.*, 2018; Howard, Van Dorn, Myers, *et al.*, 2017; de Villiers *et al.*, 2020).

The fear of being seen at a clinic accessing services, including starting and collecting ART, was a deterrent factor found by Hargreaves and colleagues (2018).The stigma associated with accessing HIV-treatment services included the anticipated stigma of people in the community finding out about clinic attendance (Hargreaves *et al.*, 2018; de Villiers *et al.*, 2020). This is also associated with lack of privacy in health facilities, PLHIV complained about being isolated from other patients which inadvertently expose their HIV status to others (de Villiers *et al.*, 2020).

The use of substances such as alcohol consumption affects decisions to link to care and adhere to treatment (Heestermans, Browne, Aitken, *et al.*, 2016; Kader, Govender, Seedat, *et al.*, 2015). PLHIV who could not accept their HIV status resorted into using alcohol as a way to escape the stress of being diagnosed with HIV (Heestermans *et al.*, 2016; Kalichman, Banas, Kalichman, *et al.*, 2020). In such cases, alcohol is seen as competing with ART treatment regimens — people consume alcohol to relief stress rather than initiating treatment. Even those who had started treatment are reported to have experienced interruptions when they engaged in recreational activities such as drinking alcohol or using drugs (Kalichman *et al.*, 2020). All these factors were found coexisting in the context of increased access and availability of HIV treatment in South Africa, and are one of many that are still hindering adherence to HIV care.

2.3 The bilateral relationship between household income and ART adherence

Several studies have documented that there is a bilateral relationship between household income and ART adherence (Bachmann & Booysen, 2003; Merten *et al.*, 2010; Oni, Obi, Okorie, *et al.*, 2002; Steinert *et al.*, 2017). It is widely reported that ART adherence affects the ability of individuals to generate income, and impact on household expenditure patterns. Conversely, household income also impacts on ART adherence and HIV care (Merten *et al.*, 2010; Sharma *et al.*, 2015). Below, I expand on how this bilateral interaction between household income and ART adherence occurs.

2.3.1 The impact of HIV and ART adherence on household incomes

In the literature, it is evident that HIV epidemic has destabilized a number of families, affecting their sources of income and livelihoods particularly in the context of sub-Saharan African region (Kibret, 2018; Sharma *et al.*, 2015; Steinert *et al.*, 2017). For instance, Steinert and colleagues (2015), in their study in Southern Africa found that the care of and loss of family members living with HIV translate into losses of household income through higher medical and funeral expenses. Earlier studies conducted in Free State and Western Cape provinces in South Africa found that the HIV burden in households resulted in changes in expenditure patterns and in turn, reductions in private savings and investments (Bachmann & Booysen, 2003; Oni *et al.*, 2002). Researchers found that supporting ART adherence of a relative means investing valuable time, energy, and financial resources into a single individual (Merten *et al.*, 2010). Hence, HIV infection poses a serious threat to the economic survival of a household (Sharma *et al.*, 2015).

A study by Young *et al.*, (2014a) found that the presence of one individual living with HIV can jeopardise the food security of an entire household. For instance, PLHIV in South Africa reported that a person living with HIV may experience a loss of income through HIV-related health complications, which may lead to reduced food intake for the entire household (Weiser *et al.*, 2010; Young *et al.*, 2014). Lack of food can lead to risky coping strategies, including the redirection of wage labour or exchange of sex for money or food, in a household which may increase economic vulnerability or exposure to HIV (Kalichman, Watt, Sikkema, *et al.*, 2012; Viljoen *et al.*, 2017).

A study by Negin and colleagues (2017) in South African peri-urban communities, found that HIV illness can result in an increased medical expenditure and HIV affected households mostly meet this by out-of-pocket spending. Out of pocket health expenditure is usually in the form of direct payments by a household towards various types of health care and can drag households already in financially vulnerable positions below poverty level (Kibret, 2018; Sharma *et al.*, 2015). Therefore, households with PLHIV need much greater support in terms of accessibility and affordability of health care to avoid economic catastrophe (Sharma *et al.*, 2015).

In countries such as South Africa which provide free access to ART from local public health facilities, considerable out of pocket expenditure can be still incurred by PLHIV through direct costs such as diagnostic tests, treatment, and travel fees to health facilities (Negin, Randell, Raban, *et al.*, 2017). PLHIV in the country reported that they faced financial hardships due to health care-related expenditures such transport, alternative sources of care such as private doctors, pharmacies, traditional healers, and income loss due to time spent seeking care (Peltzer, Friend-du Preez, Ramlagan, *et al.*, 2011; Steinert *et al.*, 2017; Treves-Kagan *et al.*, 2016).

The high costs of accessing care for PLHIV, regardless of whether they have free access to ART, is still an important issue in the context of achieving universal health coverage (Negin *et al.*, 2017). Earlier studies indicated a change in consumption patterns when households are affected by HIV and show how resources are diverted towards health care (Bachmann & Booysen, 2003; Oni *et al.*, 2002). A household impact study in the Free State province of South Africa found that households affected by HIV allocate more of their resources to expenses like food, health care, household maintenance and rent compared to households not affected by HIV. The study further showed that families affected by HIV spend less on education, clothing, transport, and personal items compared to households that are not affected by HIV (Bachmann & Booysen, 2003).

Households affected by HIV would then adopt different types of strategies to cope with their disadvantaged livelihoods, such as altering household expenditure patterns, drawing on savings, selling limited assets, or using assistance from relatives or other households (Bachmann & Booysen, 2003; Naidu & Harris, 2005). Another study similarly showed how HIV affected households in the Limpopo province of South Africa save less income, borrow money through loans, and disinvest by selling assets to help cope with the burden caused by HIV illness in their families (Oni *et al.*, 2002). In instances where loans are taken out with high interest rates or where productive assets are sold, households face the risk of long-term economic hardships (Oni *et al.*, 2002). These studies demonstrate that HIV illness in conjunction with a household's ability to support HIV treatment access for members living with HIV has a marked impact on household resourses and it alters the way they manage their incomes. But we still do not know how these changes in expenditure patterns affect the adherence of PLHIV.

2.3.2 Household income and its impact on ART adherence

Studies have shown that, in addition to the impact of ART on income and resources, vulnerable household income also impacts on ART adherence in various ways (Kibret, 2018; Steinert *et al.*, 2017). Inadequate household income constitutes as one of many delaying factors of effective ART adherence in South Africa, despite the increased accessibility of HIV treatment (Ahmed *et al.*, 2018; Seeley *et al.*, 2019). A growing number of studies have shown that the impact of vulnerable household income on ART adherence is strongly associated with factors such as lack of household resources, employment versus access to HIV care, or competing everyday priorities (Campbell *et al.*, 2020; Masquillier *et al.*, 2016;

Seeley *et al.*, 2019). For instance, Seeley *et al.*, (2018), in their study based in Zambia and South Africa, PLHIV reported that they often struggled to balance work and accessing care both which are deemed important to their livelihood. Some PLHIV who reported that they were the main breadwinners and had not started ART, stated that they would rather use their strength to earn an income and continue providing for their family, as they were still feeling healthy, than go for treatment (Negin *et al.*, 2017; Steinert *et al.*, 2017).

The time spent travelling to and attending clinical appointments places economic strain on patients and their families by competing with income generating activities (Negin *et al.*, 2017). Moreover, frequent absences from work create conditions under which employers may terminate employment if they do not know the reason for such absences. The threat of losing employment for this reason, therefore, often impedes clinic attendance (Kagee *et al.*, 2011).

Vulnerable household income can further affect ART adherence when the earned resources are not adequate to meet ends with the standards of affording 'recommended' nutrients and additional medication for ART side effects (Nagata *et al.*, 2012; Young *et al.*, 2014a). For instance, when PLHIV experience side effects from ART, such as nausea, vomiting, and stomach pains heightened by a lack of food, some chose not to take their HIV medication (Weiser *et al.*, 2010). These were the results of food insecurity, defined as "the limited or uncertain availability of nutritionally adequate, safe foods or the inability to acquire personally acceptable foods in socially acceptable ways" (Weiser *et al.*, 2010: 2). In such instances, demands for food usually compete with other household resources needed to procure medicines (Young *et al.*, 2014).

In countries where household income is low, PLHIV reported that they have difficulties in adhering to treatment, even in the context of universal access to treatment (Moosa *et al.*, 2019). Despite clinic consultations and appointments being "free" for HIV care, clinical care is not without costs (Steinert *et al.*, 2017). There are costs which include expenses required to receive care, such as payment for transportation to health care facilities (Steinert *et al.*, 2017). In cases where there is no transportation fee to travel to the clinic, PLHIV reported that they missed their appointments for collecting treatment which obstructs their ART adherence regularity (Steinert *et al.*, 2017). Below I expand on other factors affecting adherence and the ART adherence experiences of PLHIV in South Africa.

2.4 Factors affecting adherence and ART adherence experiences of PLHIV in South Africa.

As discussed above, there are several factors that affect ART adherence and many of these factors are connected to household income, including lack of resources, food insecurity, and time, or competing priorities between going to work and seeking health care (Ismail, Kari & Kamarulzaman, 2017; Steinert *et al.*, 2017; Weiser, Young, Cohen, *et al.*, 2011). In this section, I discuss how other factors in the immediate environment impact on ART adherence of PLHIV along with the ART adherence experiences of PLHIV. These factors are interrelated and include familial support, power dynamics associated with interpersonal relationships with partners, status disclosure, and HIV stigma. While these factors interact within the immediate environment, there are other interrelated factors beyond the household level, including social, cultural, and religious beliefs. I also discuss and further link these factors with the ART adherence experiences of PLHIV .

Familial support is reported to be the key element among household factors that influence the decisions of people to seek HIV testing, engage in care, and stay in care (Azia *et al.*, 2016; Horter, Thabede, Dlamini, *et al.*, 2017). Familial support starts after the status is accepted by PLHIV and voluntary disclosure to trusted family members and friends occurs, which subsequently creates the space for support (Horter *et al.*, 2017; Masquillier *et al.*, 2016). Access to social support has been found to have immediate and long-term positive influences on the adherence behaviour of PLHIV (Campbell *et al.*, 2020).

A study by Campbell *et al.*, (2020) have demonstrated that it is important to recognise the different types of support that households either offer or withdraw from PLHIV, including instrumental, emotional and informational support. For example, in the study by Campbell and colleagues (2020), PLHIV reported that they were more likely to take medication when they were reminded or accompanied by their household members to visit clinics, offered emotional support, and able to share their worries and concerns with them. This entails sharing responsibility for preventing onward transmission which is vital to the treatment journey of PLHIV(Campbell *et al.*, 2020).

Masquillier *et al.*, (2016: 2), in their systematic review publication, posited that when household support for PLHIV is characterised by behaviours supporting disclosure, discussion, and prevention, the household is deemed to be “HIV competent”. Household “HIV competency” creates a health-enabling environment for PLHIV and has positive effects on ART adherence and prevention behaviour. The household is a vital micro-environment that provides financial and emotional support to achieve optimal ART adherence (Campbell *et al.*, 2020).

However, in cases where there is lack of familial support towards ART adherence, PLHIV said that they experience difficulties in adhering to HIV treatment (Masquillier, Wouters, Mortelmans, *et al.*, 2015). This usually happens when families distance themselves from having PLHIV living amongst them due to HIV related stigma and discrimination (Masquillier *et al.*, 2015). Studies in sub-Saharan Africa show that, since the beginning of the HIV epidemic, stigma attached to HIV has been widely recognised as a significant hindrance to the effective provision of care and prevention efforts of HIV transmission (Ahmed *et al.*, 2018; Haruna, 2017; Treves-Kagan *et al.*, 2016). HIV stigma discourages PLHIV from disclosing their HIV status to family members, which ultimately affected their courage to seek health care (Haruna, 2017).

The interpersonal relationships with partners and family members also affect ART adherence behaviour of PLHIV. A study by Dlamini-Simelane & Moyer (2017) in Swaziland, found that amongst PLHIV who have accepted their HIV diagnosis, some reported that hey were afraid to disclose to partners which cause difficulties in adhering to ART. Seeley *et al.,* (2018) similarly found that a delayed disclosure of HIV status to partners, and between women to their male spouses in particular, is one of the reasons reported by PLHIV to delay attending care and starting ART in the context of South Africa and Zambia. The negotiation between spouses shapes nearly all spheres of life for married women including decisions related to health care (Dlamini-Simelane & Moyer, 2017).

Seeley *et al.,* (2018) found that many women in their study experienced gender-based violence and their dependency on their husbands affected their own decisions regarding the uptake of ART. Women reported that they placed greater value on their marital relations than on their health and stated that making health care decisions prior to consulting spouses would jeopardise those relations (Dlamini-Simelane & Moyer, 2017). Therefore, being declared eligible for ART is not a sufficient motivation to submit to a biological process that may damage marital and filial reputations (Dlamini-Simelane & Moyer, 2017). These interpersonal factors associated with health seeking behaviour are influenced by power dynamics that interplay within a household. The power dynamics further impact on how resources in households are allocated, and in turn, that has been found to affect optimal adherence to care (Kibret, 2018).

In addition to these household factors discussed above, it is important to note that household "HIV competency" and support for ART adherence may be affected by broader social aspects outside the immediate environments in which PLHIV live (Masquillier *et al.*, 2016). Broader social, cultural, and religious beliefs interfere with how households react towards ART adherence experiences of PLHIV. For instance, social inequalities trickle down to the household level, with household members possessing different levels of power and agency – where women and children are often deprived of the power to decide on their health care (Campbell *et al.*, 2020; Dlamini-Simelane & Moyer, 2017).

The popular cultural and religious beliefs on health influenced health behaviours of PLHIV. In five studies conducted in South Africa, Kwa-Zulu Natal province, PLHIV reported that they were encouraged by family members to use traditional medicine or to 'trust in God' and put less faith in ART (Iwuji *et al.*, 2016; Nlooto, 2017; Peltzer *et al.*, 2011; Plazy *et al.*, 2017; Zuma, Wight, Rochat, *et al.*, 2016). These beliefs were reported to be influenced by cultural and religious practices operating within the space of macrosystem. In contrary, religious beliefs sometimes gave household members faith to carry on supporting ART adherence of PLHIV (Zuma *et al.*, 2016).

The ART adherence experiences of PLHIV in South Africa also vary per context. PLHIV in peri-urban settings reported that, at times, they had to walk long distances to access care due to poor infrastructure and lack of local health facilities (Kagee *et al.*, 2011). Some PLHIV in resource-constrained settings reported that they deliberately stopped taking medication in attempt to continuously receive disability grant for living with HIV[1] (Kagee *et*

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[1] *Old Age Pension grant* - for persons over the age of 60 years; *Child Support grant* – for children under the age of 18 years old; *Care Dependency grant* - offers financial help to full-time caregivers of a child; *Foster Child grant* – when a person is taking care of a foster child and need financial assistance; *Grant in aid grant*- extra grant given to people already receiving a disability, old age pension, or war veterans and diagnosed with mental or physical disabilities; *Social relief grant* – temporary grant paid for a maximum of 3 months to people in desperate need of financial assistance; and Disability grant - provided to people at ages of 18 to 59 years on a basis the person is living with a disability proved by medical assessment

al., 2011). In the South African economic landscape characterized by scarce employment, disability grant became a way to generate regular income in households affected by HIV. PLHIV reported that they were eligible to disability grant if they kept their CD4 count below 200 mp (Kagee *et al.*, 2011). The PLHIV also reported that the overcrowded waiting rooms in clinics and lack of privacy during counselling sessions have made clinic attendance unpleasant (Haruna, 2017). They reported that the unpleasant experience at the clinics also include "rudeness and unkindness" by staff members which had led many to skip appointments (Haruna, 2017). To conclude, this shows that there are multiple factors affecting ART adherence in households and at the broader level, which determine the adherence experiences of PLHIV..

2.5 Theoretical Framework

2.5.1 Bronfenbrenner's Ecological Framework for Human Development

In terms of conceptual paradigm, the Bronfenbrenner's Ecological Systems Framework (1979) is appropriate to conceptualise how various factors, including how the management of incomes affect the ART adherence behaviours of PLHIV. I interpret the findings of this study using this theory.

Bronfenbrenner's Ecological Framework for Human Development was developed in the 1970s to examine the complex interactions and relationships between an individual and his or her multiple social and physical surroundings during their adolescent development (Houston, 2015). Bronfenbrenner's theory was originally conceptualised to understand how the surrounding environmental aspects impact on the child development throughout their life-course. Bronfenbrenner (1979) argues that in order to understand human development, the

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(source: westerncape.gov.za Link: https://www.westerncape.gov.za/general-publication/applying-social-welfare-grant#Foster%20child%20grant) entire ecological system in which growth occurs needs to be taken into account. "Subsequently, his work has been widely used to explain health behaviours, to spread in a raft context and has laid a determinative foundation for social works nascent, ecological perspective" (Houston, 2015: 1). Bronfenbrenner's theory (1979) encompasses five ecological systems for human development: the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem.

Microsystem

The microsystem is the immediate environment where a person is operating and spends most of their time in intimate face-to-face interactions with significant others such as the family or peer group. (Bronfenbrenner, 1971). It is here that attachments and strong bonds are formed, a secure base realised, and identity is moulded. The microsystem is the environmental factor closest to the person that have the greatest influence on their health behaviours and development (Houston, 2015). For example, when a child is raised in a family that hold strong views about a certain religion or culture, they are most likely to act and behave according to these cultural guidelines as these custom and beliefssinfluence their development.

Mesosystem

When different components of microsystems interact, the mesosystem is formed. The mesosystem encompasses the relationship between two or more settings, for instance, the relationship between family, school or peers (Bronfrnbrenner, 1979). Mesosystem represents activities and roles that overlap across the range of microsystems. "It is this rich soup of interaction that provides stimulation structure, purposive action and meaning" (Houston, 2015: 5). In the mesosystem, human development and behaviour is influence by the relationship of different entities that are part of microsystem (Bronfrnbrenner, 1979).

Exosystem

The exosystem entails broader social, political, and economic conditions, which indirectly influences the well-being of a person's development and behaviour (Bronfrnbrenner, 1979). The person may not be a part of this system but nevertheless is affected by its influence. For instance, a parent who is made unemployed by his workplace (a part of the exosystem) becomes depressed at home and this has an understandable effect on their family members. This system is therefore more distant from the subject and often takes on an institutional form that indirectly has a knock-on effect for the micro and mesosystems (Peppler, 2017).

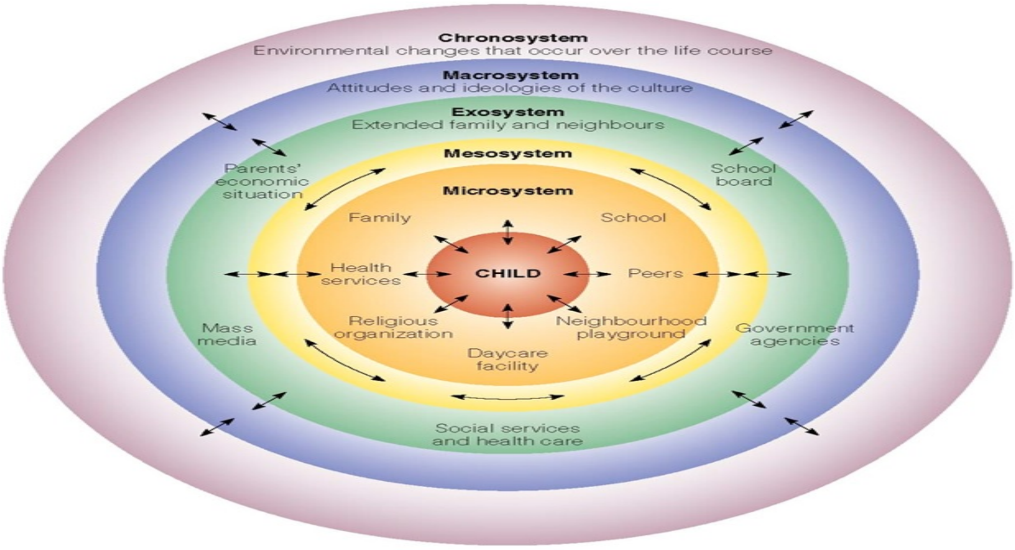
Macrosystem

The macrosystem represents the value, ideologies and laws of the culture or society. Social rules and ideologies distinguish one culture or country from another, as well as different sub-cultures within a single country (Bronfenbrenner, 1979). It is the arena where social and political policy is formed. For instance, how a state deals with inequality and distribution of wealth has major impact on the development of a person and family well-being. A practical example would be the HIV denialism by the South African government between 1999 and 2008 where PLHIV did not have access (see section 2.1).

Chronosystem

The chronosystem is argued to be the time-based dimension that can alter the operation of microsystem, mesosystem, exosystem, and macrosystem. The individual and their developmental behaviour undergo changes over time due to circumstances and life conditions such as illnesses or accidents that come up (Bronfenbrenner, 1979). Other changes include external factors such as mobility, change in public policy, culture, or tradition, which ultimately influence the behaviour of an individual (Bronfrnbrenner, 1979; Peppler, 2017). . For example, a child who grew up inspired to be a teacher but experiences some illness at home and over time they end up being enthusiastic to become a doctor. The diagram below shows all five layers of Bronfenbrenner's Ecological Framework , 1979.

Figure 1: *Bronfenbrenner's Ecological Framework (1979)*



Source: (Getty images, 2008)

As shown above (Figure 1), an individual is involved in a series of the environmental systems are interrelated and that interact with one another. This theory demonstrate that the development of an individual occurs within various contexts; within family, history, culture, society and economy. The microsystem, mesosystem, and chronosystem have a direct influence on an individual's behaviour while exosystem and macrosystem have the indirect impact (Bronfenbrenner, 1979). The interaction between an individual and others is important, but the relationships and interconnectedness among other environmental systems also affect the individual behaviour.

The theory was conceptualised to understand human development, but it has been applied extensively in other fields including health behaviour research. Through the use of this theory, many studies have shown how external factors are determinants of health behaviours, in addition to biological aspects (Darling, 2007; Maphalala & Ganga, 2014; Reifsnider, Gallagher & Forgione, 2005). A study by Darling (2007) in the context of sub-Saharan Africa posited that health behaviours are thought to be maximised when immediate environments and public policies support healthful choices, individuals are motivated and educated to make those choices. However, educating people to make healthful choices when immediate environments are not supportive can be less effective (Darling, 2007).

2.5.2 The importance of Bronfenbrenner's theory in this study

I have adapted the lens of Bronfenbrenner's theory to interpret and provide an in-depth analysis of my findings. This theory is suited for this study because it provides the framework against which the direct and the indirect factors affecting ART adherence of PLHIV at the household level can be interpreted and understood. In this study, I show how factors located at the microsystem, mesosystem, exosystem, macrosystem, and chronosystem are interconnected to each other and the major influence they have on the the immediate environments in which PLHIV live. The relationship and the impact of these systems cannot be cast out when explaining how the management of incomes affect adherence behaviours of PLHIV. I use the lens of this theory to contextualise how families 'got by' and managed their incomes. I further show how factors located at different systems influenced the ART adherence experiences of PLHIV.

Chapter 3: Methods

In this chapter, I expand on the methods employed for the study. Firstly, I describe the research design. Then, I provide a detailed description of the HPTN 071 (PopART) trial, in which my project is nested. I also describe the study setting and my study sample. Thereafter, I expand on the data collection process, the analysis, and reflect on the trustworthiness of the study. Lastly, I provide a description of the ethical considerations for the study and reflect on my position in the study.

3.1 Research Design

A research design is a strategic framework of plan that guides research activity to ensure that sound conclusions are reached. The research design influences the methods of the study including sampling, data collection, and analysis (Terre Blanche, Durrheim & Painter, 2006). I adopted a research design focusing on analysing qualitative data. Research with qualitative data "allows the researcher to study selected issues in depth, openness, and detail as they identify and attempt to understand the categories of information that emerge from the data" (Terre Blanche *et al.*, 2006: 272). Researchers collecting qualitative data do so in the form of written or spoken language, or in the form of observations that are recorded in language (Kelly, 2006a).

Additionally, I adopted a descriptive research paradigm, in which I aim to describe the phenomena accurately, through narrative-type descriptions (i.e. describing the ART adherence experiences of PLHIV) (Durrheim, 2006). According to the ontology of this paradigm, the researcher believes that the reality to be studied consists of people's subjective experiences of the external world (Crotty, 2003). This further allows the researcher to undertake intersubjective or interactional epistemological stance[2] towards that reality and use

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[2] Epistemology refers to the nature of the relationship between the researcher (knower) and what can be known (Terre Blanche *et al.*, 2006).

methodologies, such as interviewing or participant observation (Terre Blanche *et al.*, 2006). Therefore, the descriptive approach is appropriate for this project as I aimed to provide an in-depth qualitative data analysis and detailed narratives of PLHIV regarding their ART adherence experiences.

3.2 The HPTN 071 (PopART) trial

In this study, I draw on data collected as part of a large-scale HIV-prevention trial called HPTN 071 – Population Effects of Antiretroviral Therapy (ART) to Reduce HIV Transmission (PopART) (Hayes *et al.*, 2014). "The HPTN 071 (PopART) study is a three-armed-community cluster randomised trial that measured the impact of a combination prevention intervention on population level HIV incidence in South Africa and Zambia" (Hayes *et al.*, 2014: 3). The PopART study took place in 21 communities, 12 across Zambia and 9 in the Western Cape of South Africa (Hayes *et al.*, 2014).

These study communities were randomly allocated to one of three study arms – Arms A, B and C. Arms A and B received HIV combination prevention package delivered at household a level (Hayes *et al.*, 2019). Community members from Arm A were also eligible for ART regardless of CD4 count, while people in Arm B received treatment as per national guidelines. Arm C was the control arm receiving standard of care(Hayes *et al.*, 2014). In 2016, the South African national HIV treatment guidelines changed and all PLHIV were eligible for treatment, regardless of their CD4 count and the intervention in the trial was adapted accordingly, which means that treatment for all was implemented to all study communities (Hayes *et al.*, 2019; NDOH, 2016).

As part of the social science component of the trial in South Africa, a nested evaluation included a qualitative cohort of 89 families recruited in all nine South African study communities. Some families were recruited between August and December 2015, while the majority were recruited between March and July 2016 (Hoddinott *et al.*, 2018; Viljoen *et al.*, 2020). The sampling approach was purposeful, focusing on people at greater risk of HIV acquisition and who are more socially marginalized including men who have sex with men, female sex workers, transgender women, and young people aged 15 to 24 (Viljoen *et al.*, 2020). The qualitative cohort was structured in a manner that contextualised the experiences of people living with HIV and more largely, people who are living in the context of the HPTN 071 (PopART) intervention.

3.3 Setting

My study focused on the 6 PopART intervention communities in the Western Cape of South Africa (Arms A and B). The areas I focused at include communities that are located within the City of Cape Town metro and in the Cape Winelands. The Western Cape previously recorded the lowest number of PLHIV in the country, sitting at 5% in 2012 (Shisana *et al.*, 2014). However, as noted in Chapter 1, in 2017 the Western Cape province accounted for 8.9%, showing a worrying increase of 3.9% from 2012 (Simbayi *et al.*, 2018). The Western Cape province recorded the highest number of new infections compared to other provinces within the time frame between 2012 – 2017 (Simbayi *et al.*, 2018). Poverty, stigma, poor health services, mobility, household income and poor ART adherence are cited as major factors contributing towards the new HIV infections in the Western Cape (Hoddinott *et al.*, 2018; Johnson, Dorrington & Moolla, 2017; Seeley *et al.*, 2019; de Villiers *et al.*, 2020). The data for my study was collected from communities in this province.

3.4 Data sources

In my study, I analysed data collected as part of the qualitative cohort nested in the larger trial (Viljoen *et al.*, 2020). The qualitative data were collected by myself and a team of trained Social Science researchers using participatory and ethnographic approaches to understand HIV care and testing in various social contexts (Hoddinott *et al.*, 2018). The interviews with the families (households) included questions that were designed in an open-ended and questionnaire manner where we were using discussion guides to facilitate conversations (see attached Appendix A - B). Some discussions were with groups while others were with individuals, depending on the topic. We collected data in teams, where one person would be assigned to be responsible for data collection at a given household while the other person would assist. This was a team-based approach used to enhance participatory engagement with the participants and to eliminate the influence of a single researcher, and that is an important aspect for a qualitative research (Kelly, 2006).

The discussions centred on thematic module focusing on; household and family structures; place, space and movement; how they get by (income and expenses); love, sex and romance; understandings and experiences of the intervention or HIV prevention; and hopes, fears and ambitions. The languages that were used in discussions were isiXhosa, Afrikaans, and English, depending on the home language of participants.

We recorded all discussions and took photos during data collection, and further made observational and reflective notes as part of this process. Households were visited on the average of 8 to 15 times each and researchers would spend approximately 1 to 3 hours with the household per visit. Data collection took place over a period of 18 months between 2016 and 2017 (Viljoen *et al*., 2020). The recorded interviews were transcribed verbatim, double-checked for errors and thereafter, translated into English by myself and the Social Science team from Desmond Tutu TB Centre, Stellenbosch University.

3.5 Sample

In the qualitative cohort nested in the PopART trial, there were 37 households in the intervention communities with members who self-disclosed that they were living with HIV. I excluded 24 households where participants living with HIV did not participate in one-on-one interviews focused on health care and treatment access (see attached Module 4 interview guide). I included 10 men and 11 women living with HIV, ranging in age between 18 to 70 years from 13 selected households across the 6 communities located in the South African PopART intervention arms . I used the sampling to redundancy technique to select the 13 households, where I continued the selection of cases for inclusion until further selection no longer yielded significant new information (Terre Blanche *et al.*, 2006).

3.6 Data analysis

For my study, I included and analysed 25 verbatim transcribed interviews, informed by additional fieldwork notes. As part of the analysis, I employed a thematic approach. Thematic analysis is an approach used to analyse qualitative data that involves identifying themes or patterns in the data (Braun & Clarke, 2006). Guest *et al.,* (2014) describe thematic analysis as a technique used to extract desired information from a body of material, usually from transcribed interviews. Thematic analyses "move beyond counting explicit words or phrases and focus on identifying and describing both implicit and explicit ideas within the data, that is, themes" (Guest, MacQueen & Namey, 2014: 9). The thematic approach is useful for theorising across a number of cases – finding common elements across research participants and the events they report (Braun & Clarke, 2006).

I conducted thematic analysis by following six steps outlined by Attride-Stirling (2001) for coding and theme development. These steps include; (i) coding the material; (ii) identifying themes; (iii) constructing thematic networks; (iv) exploring thematic networks; (v) summarizing thematic networks and; (vi) interpreting the patterns. I used Atlas.ti, a computer software programme for organising qualitative data, for coding (Friesie, 2019). I created codes, linked, and grouped them according to their relevance using this software programme (see detailed description below). I adopted deductive approach which means coding was informed by pre-existing theoretical interests guiding research questions (Terre

Blanche *et al.*, 2006). These tools increased the methodological rigour and sophistication of my analysis. Below are the six steps I followed to analyse data.

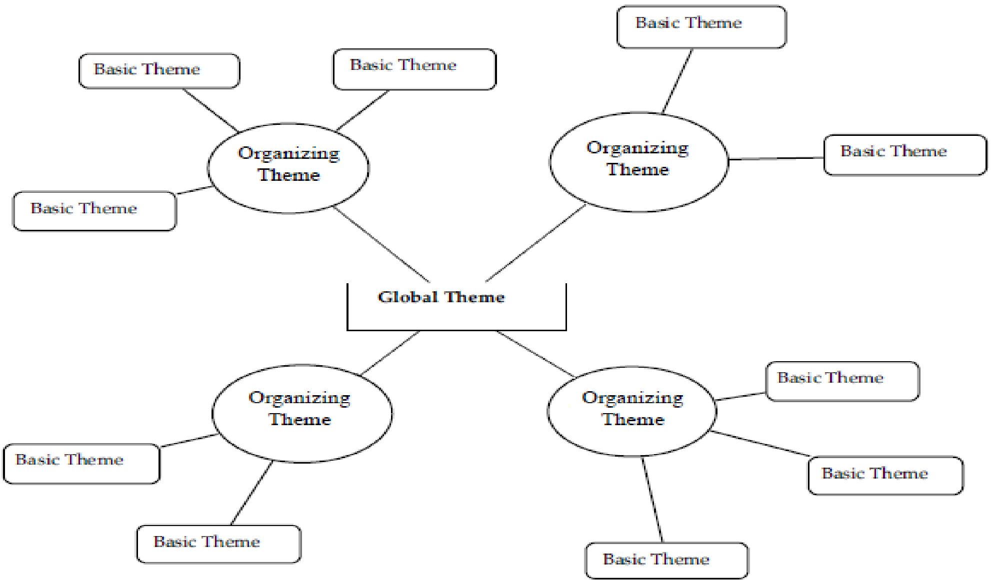
1. Coding the material. As a first step, I had to familiarise myself with the data through transcribing the recorded interviews and reading through transcripts that had already been transcribed while making notes (Attride-Stirling, 2001). On the transcribed data, I coded the material deductively by marking and dissecting the relevant pieces of text segments aside using the Atlas.ti platform. For my research focus, this included coding broadly for descriptions of how families 'get by'; how households manage incomes; and sections of text where ART and adherence behaviour was described.

2. Identifying themes. Secondly, I grouped the codes (or group of related codes) into clusters i.e., assembled them into themes. I went through the text segments in each group of codes, and extracted the salient, common, or significant themes in coded text segments. This stage involved sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes (also see Clarke & Braun, 2006). Thereafter, I refined the themes to reduce repetitiveness and succinctly summarised the meaning provided by text segments.

3. Constructing the networks. Thirdly, I rearranged the themes into similar, coherent groupings that constructed thematic networks. "Thematic networks are web-like illustrations that summarize the main themes constituting a piece of text" across various levels (Attride-Stirling, 2001; p1). As a first step of constructing thematic networks, I grouped similar codes into basic themes. Thereafter, I rearranged the basic themes into organising themes, which ultimately became global themes (see Figure 2 below).

A basic theme is the most basic or lowest-order theme that is derived from the textual data and an organizing theme is a middle-order theme that unifies the basic themes into clusters of similar issues (Attride-Stirling, 2001). A global theme is a main assertion or claim encapsulating the main point of the text segment (Attride-Stirling, 2001).

Figure 2: *Structure of thematic networks.*



Source (Attride-Stirling, 2001: 388)

4. Exploring thematic networks. I described and explored thematic networks through rereading global, organising and basic themes in a back-and-forth manner (Attride-Stirling, 2001). At this stage, I provided text segments from the original transcript/data to support the analysis. This means after describing each thematic network, I went through original data (transcript) and retrieved a quote (from coded texts) that best captures the whole meaning of the identified thematic network (Attride-Stirling, 2001).

5. Summarize thematic networks. After I described and explored the thematic networks in full, I presented the summary of the main themes and patterns characterizing them (Attride-Stirling, 2001). I began to make explicit the patterns or themes that were formulated during exploration.

6. Interpret patterns. As a last phase, I interpreted the patterns (or themes) in accordance with the original research question and theoretical interests underpinning them. In my research, this meant that I used theoretical framework of Bronfenbrenner (1979) to contextualise how families 'get by' and manage their incomes. Moreover, data interpretation was also based on the recurrent and prominent issues found on transcripts (Attride-Stirling, 2001).

In summary, although the stages are presented in a linear order, the analytic process is in reality an iterative process whereby there is an ongoing moving backwards and forwards between the phases (Nowell, Norris, White, *et al.*, 2017). Additionally, it was appropriate for the study to adopt thematic approach or structure by Attride-Stirling (2001) because I aimed to thematically organise how families 'get by' and manage incomes. This was done in preparation to provide an in-depth analysis and description on how the management of incomes affect ART adherence behaviour of PLHIV.

3.7 Trustworthiness

Trustworthiness in a study is evaluated through various ways in order to ensure the rigour of a study (Kelly, 2006b). In qualitative research, the most widely accepted criteria to achieve trustworthiness include (i) credibility; (ii) transferability; and (iii) dependability (Kelly, 2006b). Below is how I achieved trustworthiness in this study.

3.7.1 Credibility

Credibility refers to the degree to which research conclusions are sound (Kelly, 2006b; Terre Blanche *et al.*, 2006). A credible research produces findings that are convincing and believable and that is usually achieved through triangulation which entails employing various methodologies (Kelly, 2006b).

I achieved triangulation in the study through adopting three (data, theory and methodological) of four basic types of triangulations identified by Denzin, 1978. Data triangulation refers to the use of variety of data sources, theory triangulation refers to the use of multiple perspectives to interpret data, and methodological triangulation refers to the use of multiple methods to study a single problem (Denzin, 1978).

In the study, I achieved credibility by using data collected by various researchers which ultimately limits the influence of a single researcher (Denzin, 1978). Additionally, during data collection we used different data collection methods such as interviewing, participant observation and surveying (Kelly, 2006). I also used pictures and questionnaires completed by participants to validate data. Lastly, the interviews I analysed were transcribed verbatim, directly translated and double checked for quality to ensure accuracy of the data.

3.7.2 Transferability

Transferability refers to the degree to which the findings from one study in a specific context can be transferred to other settings (Drisko, 2013). To create foundation for transferability and allow other researchers to use findings in other contexts, a research report must contain an 'accurate description of the research process' and secondly an explication of the arguments for different choices of the methods (Smaling, 2003: 88). Additionally, it should provide 'a detailed description (thick description) of the research situation and context' (Smaling, 2003: 88).

To address transferability, I provided a "thick description" – a rich, detailed description of the sampling process, the participants & families involved, the context in which the study was conducted (Nowell *et al.*, 2017). I also described the procedures of data collection and analysis, and the comprehensive findings (Kelly, 2006b; Nowell *et al.*, 2017). Furthermore, I described in detail the different method choices I adopted in the study in the section above.

3.7.3 Dependability

Dependability refers to the degree to which the reader can be convinced that the findings did indeed occur as the researcher says they did (Durrheim, 1999). It is achieved through rich and detailed descriptions that show how certain actions and opinions are rooted in, and developed out of, context interactions (Terre Blanche *et al.*, 2006). Dependability is also achieved by providing the reader with a clear statement of the methods used to collect and analyse data.

To attain or demonstrate dependability, I attached various documents to show that the steps in the research project can be tracked (Nowell *et al.*, 2017). I include the two discussion guides that were used to collect the data I analysed (see Appendix A and B). I also attached excerpts from the transcription guide used to process data (Appendix C), and shown a structure illustrating the development of themes (see section 3.7.1). In addition, the data I used, including audio recordings, verbatim transcripts, and fieldwork notes, will be anonymised and made available (under strict ethical considerations and procedures) should it be requested by the reader.

3.8 Ethical Considerations

The essential purpose of research ethics is to protect the welfare of research participants. Research ethics, however, involves more than a focus on the welfare of research participants and extends into areas such as scientific misconduct and plagiarism (Wassenaar & Mamotte, 2012). In this study, I maintained the principles of ethical social research influenced by the works of Nuremberg Code 1948 and Declaration of Helsinki 1964 found on (Ambur, 2003).

3.8.1 Ethical clearance

The ethics approval of this study was granted by the Health Research Ethics Committee (HREC) at Stellenbosch University (Ref no. S19/10/227) (see Appendix E). Additionally, since the study has drawn on data collected in the context of the HPTN 071 (PopART) trial, permission to use data for the use of this research project was granted by the principal investigators of the larger trial (see attached Appendix F). All participants in the study signed written informed consent documents (See appendix D) and consent was repeatedly confirmed during the data collection process.

3.8.2 Confidentiality and Anonymity

To ensure I maintain confidentiality and anonymity, protection of participants' identities and firm security measures were taken. All the data used in this study is highly protected through appropriate security measures. The hard copies of fieldwork notes, consent forms and transcripts are stored in the locked cabinets. The electronic copies of the recordings, transcripts and consent forms are kept on password-protected computers where the access is limited to myself and other authorized staff from the Desmond Tutu TB center. I anonymised any data presented publicly by removing all identifiers of participants (and families) and replaced them with codes and/or pseudonyms.

3.8.3 Risks and Benefits

This study used data already collected as part of the larger HPTN 071 (PopART) trial and no further contact was made with participants for any additional information or retrieval of new data. Therefore, there were no direct benefits, or any risks imposed by this study to participants or families whose data was used. There were no direct benefits or risks imposed by HPTN071 (PopART) study either. During PopART data collection, families had the opportunity to share and speak out their experiences, which to some, ultimately provided ease and relief. However, some of the questions asked during data collection were sensitive and might have triggered discomfort to participants.

3.8.4 Informed consent and Voluntary participation

As indicated above, no further contact was made with participants in this study. During PopART data collection the consent forms were succinctly explained and written in the form of language that the participants well understood. Moreover, the consent was continuously reaffirmed during data collection. The participants were asked if they agree to have their data included for future analyses as part of the Social Science databank. Only the data from participants who gave right of permission for secondary analysis was used in this study. All participant completed an informed consent document (Appendix C).

3.8.5 Budget and funding

The costs of data collection process such as visits, travel fees, tools for data collection, and other materials used for research are already incurred by the HPTN071 (PopART) study. Therefore, no further costs or major use of funds are involved in this study. I completed this thesis while employed at this Desmond Tutu TB Centre and received additional financial support from the National Research Fund.

In this chapter I described how I conducted the study. First, I gave description of the study research design, the context of the HPTN 071 (PopART) trial, the study setting, and the study sample. Thereafter, I clarified how the data was collected and analyzed, followed by how I achieved trustworthiness of the study. Lastly, I described the ethical procedures and considerations undertaken in the study.

Chapter 4: Findings

In this chapter, I present the key findings from the 13 selected families affected by HIV. As noted in Chapter 3, these families all live in communities included in the South African HPTN 071 (PopART) intervention arms in the Western Cape province. As stated in Chapter 1, the objectives of this study were to describe the patterns in which households affected by HIV 'get by'; to thematically organize how incomes are managed by households affected by HIV and; to provide a thematic representation on how the management of household incomes affect ART adherence of PLHIV.

The findings of this study are structured according to these objectives. I begin this chapter by providing an overview of the demographics of the selected families in Table 1 below. Thereafter, I present a diagram (see Figure 3) demonstrating the sections and sub-sections included in this chapter.

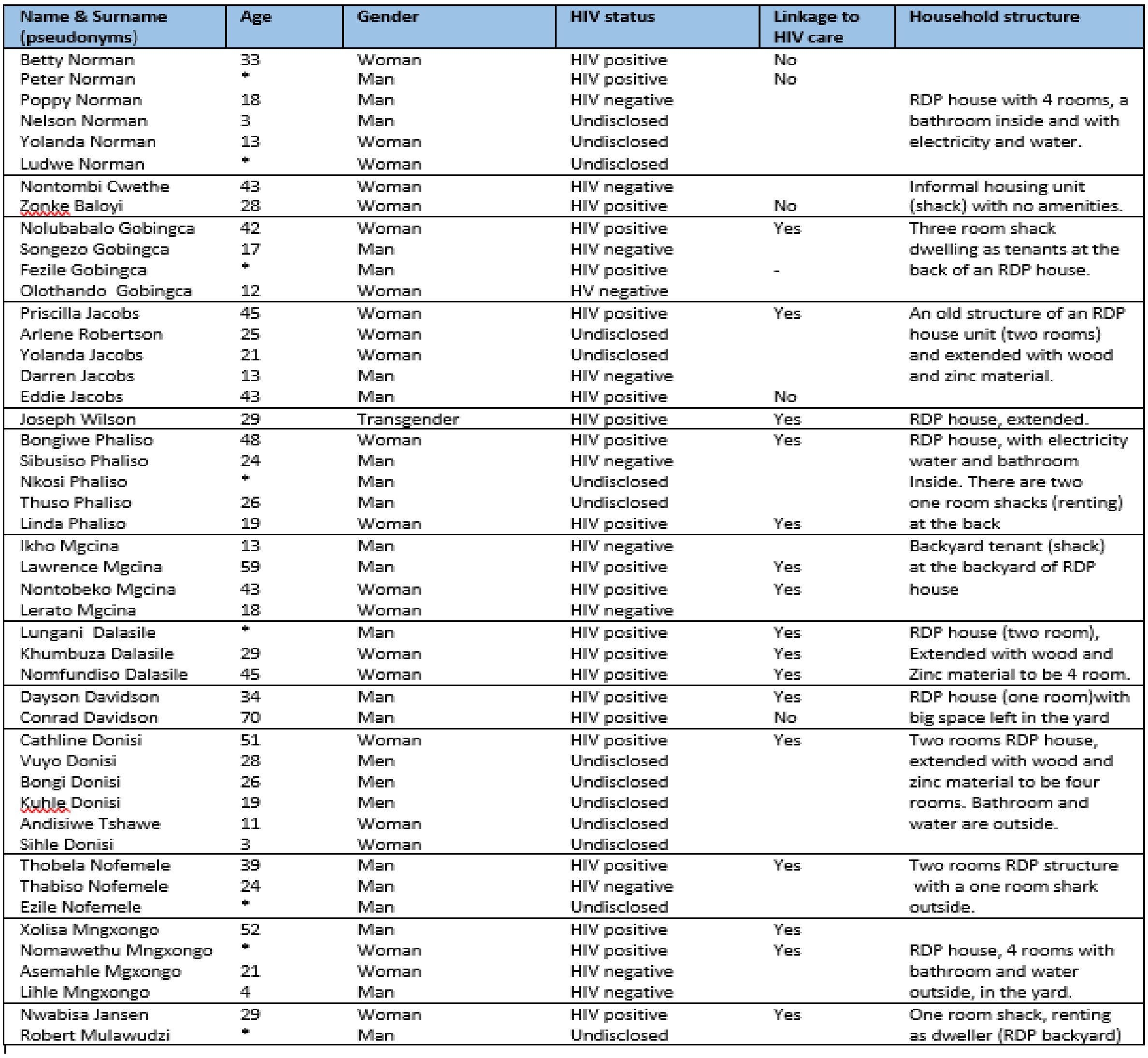
Following the overview of demographics and the diagram, I provide a description of how families affected by HIV 'get by', including ways people secure the means to survive including aspects such as begging, selling assets, borrowing, or through employment (Smeeding & Weinberg, 2001). This is followed by a description of the prominent ways in which these families manage their incomes. The management of household incomes include how resources are organised, the decisions around incomes, and the household priorities and expenditure patterns.

Lastly, I discuss how the management of incomes potentially influenced the treatment adherence behaviour of PLHIV in the context of increased access to HIV testing and treatment. In this section, I describe how PLHIV could move from being non-adherent to being adherent on ART, and given these fluid life conditions, treatment adherence could be interrupted.

4.1 Household and participant demographics

The demographics of the 13 households affected by HIV selected for the analysis are presented in Table 1 below. In the table, I include the pseudonyms (name and surname) assigned to participants, along with their age and gender, the HIV status of all household members (self-reported), the status of linkage to care of PLHIV (self-reported), and a characterisation of the physical household structure. Table 1 comprise all household members who form part of the immediate family (or household) of the participating PLHIV. The average number of members per household is four.

***Table 2**: Demographics, self-reported HIV status, and characterisation of the physical household structure for families included in the study* [3]



Name & Surname (pseudonyms)	Age	Gender	HIV status	Linkage to HIV care	Household structure
Betty Norman	33	Woman	HIV positive	No	RDP house with 4 rooms, a bathroom inside and with electricity and water.
Peter Norman	*	Man	HIV positive	No	
Poppy Norman	18	Man	HIV negative		
Nelson Norman	3	Man	Undisclosed		
Yolanda Norman	13	Woman	Undisclosed		
Ludwe Norman	*	Woman	Undisclosed		
Nontombi Cwethe	43	Woman	HIV negative		Informal housing unit (shack) with no amenities.
Zonke Baloyi	28	Woman	HIV positive	No	
Nolubabalo Gobingca	42	Woman	HIV positive	Yes	Three room shack dwelling as tenants at the back of an RDP house.
Songezo Gobingca	17	Man	HIV negative		
Fezile Gobingca	*	Man	HIV positive	-	
Olothando Gobingca	12	Woman	HV negative		
Priscilla Jacobs	45	Woman	HIV positive	Yes	An old structure of an RDP house unit (two rooms) and extended with wood and zinc material.
Arlene Robertson	25	Woman	Undisclosed		
Yolanda Jacobs	21	Woman	Undisclosed		
Darren Jacobs	13	Man	HIV negative		
Eddie Jacobs	43	Man	HIV positive	No	
Joseph Wilson	29	Transgender	HIV positive	Yes	RDP house, extended.
Bongiwe Phaliso	48	Woman	HIV positive	Yes	RDP house, with electricity water and bathroom Inside. There are two one room shacks (renting) at the back
Sibusiso Phaliso	24	Man	HIV negative		
Nkosi Phaliso	*	Man	Undisclosed		
Thuso Phaliso	26	Man	Undisclosed		
Linda Phaliso	19	Woman	HIV positive	Yes	
Ikho Mgcina	13	Man	HIV negative		Backyard tenant (shack) at the backyard of RDP house
Lawrence Mgcina	59	Man	HIV positive	Yes	
Nontobeko Mgcina	43	Woman	HIV positive	Yes	
Lerato Mgcina	18	Woman	HIV negative		
Lungani Dalasile	*	Man	HIV positive	Yes	RDP house (two room), Extended with wood and Zinc material to be 4 room.
Khumbuza Dalasile	29	Woman	HIV positive	Yes	
Nomfundiso Dalasile	45	Woman	HIV positive	Yes	
Dayson Davidson	34	Man	HIV positive	Yes	RDP house (one room)with big space left in the yard
Conrad Davidson	70	Man	HIV positive	No	
Cathline Donisi	51	Woman	HIV positive	Yes	Two rooms RDP house, extended with wood and zinc material to be four rooms. Bathroom and water are outside.
Vuyo Donisi	28	Men	Undisclosed		
Bongi Donisi	26	Men	Undisclosed		
Kuhle Donisi	19	Men	Undisclosed		
Andisiwe Tshawe	11	Woman	Undisclosed		
Sihle Donisi	3	Woman	Undisclosed		
Thobela Nofemele	39	Man	HIV positive	Yes	Two rooms RDP structure with a one room shark outside.
Thabiso Nofemele	24	Man	HIV negative		
Ezile Nofemele	*	Man	Undisclosed		
Xolisa Mngxongo	52	Man	HIV positive	Yes	RDP house, 4 rooms with bathroom and water outside, in the yard.
Nomawethu Mngxongo	*	Woman	HIV positive	Yes	
Asemahle Mgxongo	21	Woman	HIV negative		
Lihle Mngxongo	4	Man	HIV negative		
Nwabisa Jansen	29	Woman	HIV positive	Yes	One room shack, renting as dweller (RDP backyard)
Robert Mulawudzi	*	Man	Undisclosed		

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[3] Age undisclosed: [*] \| Refers to linkage to care is undisclosed: [-] \| Linkage to care: Blank space means not applicable.

As shown in Table 1, there are 21 PLHIV from 13 households included in the study; 10 men and 11 women between the ages of 18 and 70 years, with an average age of 28 years. Amongst the 21 PLHIV, 15 people (6 men and 9 women) were adherent to care i.e., PLHIV who at the time of the interview, self-disclosed that they were taking HIV treatment prescribed by a health care provider. Eleven of the PLHIV included for analysis lived in government subsidised Reconstruction and Development Programme (RDPs) houses[4], three participants resided as rent-paying tenants, while four participants lived in informal housing units roughly made of wood and zinc, commonly referred to as shacks[5]. In the following section, I present a web-like diagram of the thematic sections and sub-sections of this study according to which the findings below are structured.

Thematic overview

The following diagram illustrates the sub-sections that are contained under each of my study objectives. I include the overarching ways in which families 'get by' and manage their incomes. In the diagram, I also show that there is fluidity in how PLHIV adhere to treatment. I show that, at times, PLHIV are inclined to being adherent, but at other times, they interrupt treatment or become non-adherent due to different emerging life conditions.

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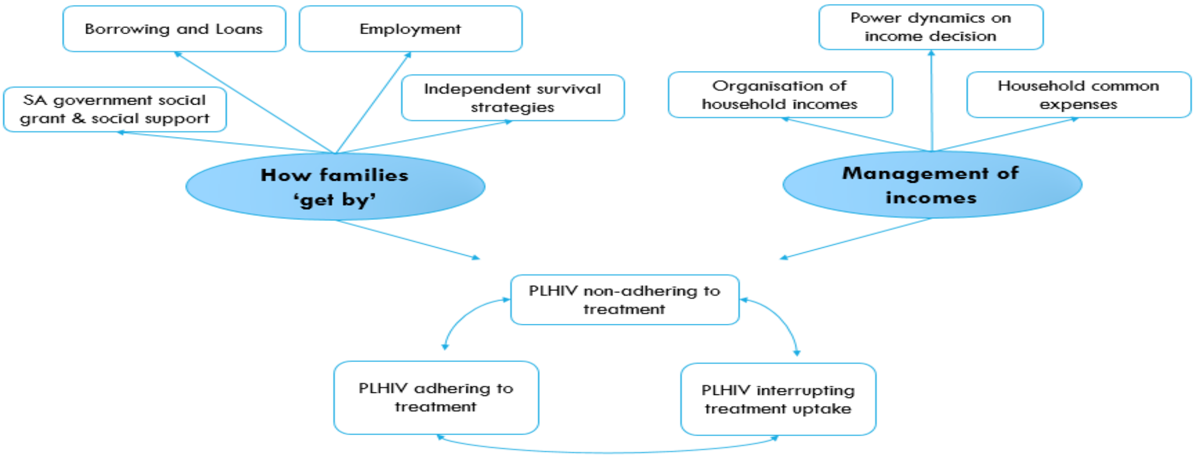
[4] RDPs are housing subsidies that are made of bricks with circuited electricity and water with enough space to qualify as a backyard and they are built by the government and given at no cost to low income families (National Department of Human Settlement, 2021)

[5] A shack refers to a roughly built hut or cabin usually located in an informal settlement (Malinga, 2000).

Figure 3: *Thematic overview of findings*



As the unit of analysis, I describe how families 'got by' and managed their incomes at the household level, while ART adherence is described at the individual level. The sections and sub-sections shown in the diagram above are discussed in detail below.

4.2 How families 'get by'

From the data, I found that households affected by HIV 'get by' through various ways. I found that there are four prominent patterns of how families 'get by' including: South African government grants and social support; borrowing and loans; employment (formal and informal); and independent survival strategies. I describe these patterns below with illustrative quotes.

4.2.1 South African government social grant & social support

Families affected by HIV reported that that they received financial assistance from the South African government's social grant system through the South African Social Security Agency (SASSA). This income was supplemented at the interpersonal level when relatives, friends and neighbours gave food parcels, money, and provided assistance with basic needs to these families.

Government social grants. The South African government social grants include Old Age Pension grant, the Disability grant, the Child Support grant, the Foster Child grant, Grant in Aid, Social Relief of Distress grant and the Care Dependency grant[6]. In South Africa, as of 2020, there were approximately 17.8 million people receiving government grants (SASSA, 2020). In this study, many participating families reported that they receive social grants such as child support grant, disability grant, and old age pension grant. Households including the Norman family, the Mgcina family, the Donisi family, the Phaliso family, and the Jacobs family described the social support grant money as being essential to their livelihoods. For instance, in the Phaliso family, Bongiwe (woman, 42, living with HIV) lives in an RDP house with her adult son and daughter who is also living with HIV. Bongiwe is also the primary caregiver of her sister's two adult children, Sibusiso (man, 24) and Thuso (man, 26), who are both living with physical disabilities. Bongiwe claims that she had forcefully taken away the SASSA grant cards of Sibusiso and Thuso from their mother in order to access funds to care for them. The SASSA cards are used by caregivers to access the grant. Bongiwe described her sister as 'irresponsible and alcohol-drinking' and insisted that by taking the card, she could take better care of the two young men. Bongiwe also received a disability grant for living with a chronic illness (high blood pressure). Below she explained how the money from the social grants help for essentials at home.

> *The grocery is also included in the social grant money, you see. Mine is R1500 and add the one [R1000] for rent [from tenants] then the children's money*

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[6] *Old Age Pension grant* - for persons over the age of 60 years; *Child Support grant* – for children under the age of 18 years old; *Care Dependency grant* - offers financial help to full-time caregivers of a child; *Foster Child grant* – when a person is taking care of a foster child and need financial assistance; *Grant in aid grant*- extra grant given to people already receiving a disability, old age pension, or war veterans and diagnosed with mental or physical disabilities; *Social relief grant* – temporary grant paid for a maximum of 3 months to people in desperate need of financial assistance; and Disability grant - provided to people at ages of 18 to 59 years on a basis the person is living with a disability proved by medical assessment (source: westerncape.gov.za Link: https://www.westerncape.gov.za/general-publication/applying-social-welfare-grant#Foster%20child%20grant) [7] A 'blesser' is an informal word referring to a male who is older than his multiple girlfriends who he has chosen to spoil with extravagant gifts in exchange for sexual favours or companionship (Mampane, 2018)

> *[disability grant] buys groceries and things for school. It then bus again, maybe, things they [children] want, like clothes.*

Bongiwe showed us how important it is to receive social grants for the household as she covers expenses like basic needs, including health care costs and school expenses with the money.

This is similar to the conditions in the Donisi household. Cathline (woman, 51, living with HIV) is staying with her three sons, Bongi (26), Vuyo (28), and Kuhle (19); her stepdaughter Andisiwe (11); and granddaughter Sihle (3). Although both Bongi and Vuyo are working at the nearby local supermarket, neither contribute funds to the household. Cathline reported that she relies on social grants for survival:

> *I don't have other reliable sources of income besides the grant money. I only get R1500 for being sick [disability grant] and then it's the one [R1000] for this three-year-old one [granddaughter] which is about R350. It's the only one. If I buy food and whatever is important, the following month I'd buy school stuff, the next it's groceries.*

This conveys the necessity of government's social grant on households, including households affected by HIV. This also shows that some families are financially constrained and depend on the income they receive from the government for survival.

Interpersonal social support. Some families reported that they receive additional support at the interpersonal level when their income is supplemented by relatives, friends, or neighbours whenever they run out of funds. For instance, in the Davidson family, Dayson (man, 34) shares the house with his father Conrad (man, 70) and both men are living with HIV and were unemployed at the time of the interview. While Dayson's father receives the old age pension grant, he did not share it with Dayson. Dayson reported that he receives support from his relatives and neighbours for survival. For example, when he was asked by the researchers how he spends money, he said:

> *What money? I don't even spend money. I am unemployed. Where do I get the money to spend? It's the people here [neighbours]. Look, you see all the people and everyone here loves me. So here I'm having a lot of food [from people around] I don't worry. I don't know where to go with all these things [food parcels]. You must come and eat here with me at some time.*

Dayson implied that he has access to so much food from his neighbours and friends that he had enough to share with others, including the researchers. Despite not having a 'fixed' income, he appeared to survive well with the help of community members and neighbours.

Nontombi (woman, age 43) who lived with her partner, Zonke (woman, 28, living with HIV), worked as a sex worker and she mentioned that one of her clients was also her 'blesser'[7]. Nontombi has a daughter who lived with her. She reported that the 'blesser' would help her out in time of financial need or when business was slow.

> *I've got a person, I call him blesser. If I ask something for my child, he comes and give me money just like last week. I wasn't there [at work]. I was at home [and] he came and gave me something .The other time he gave me money to go to the doctor.*

Nontombi has a fairly regular income through sex work, but received additional moneys from her 'blesser'. The money was not directly for services she rendered, as with her other customers, but as an additional social favour or as a support measure. Both Nontombi

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[7] A 'blesser' is an informal word referring to a male who is older than his multiple girlfriends who he has chosen to spoil with extravagant gifts in exchange for sexual favours or companionship (Mampane, 2018)

and Dayson received support from their close networks – either in the form of food from neighbours, as Dayson did, or in the form of financial support, as Nontombi did.

4.2.2 Informal borrowing and loans

Many household would regularly run out of basic necessities before they could access their next income. To counter this situation, the families were often forced to secure short term loans from informal lenders, commonly referred to as 'loan sharks'. 'Loan sharks' are money lenders who charge extremely high rates of interest, typically under illegal conditions with strict terms of collection upon failure to repay (Bond, 2018). Borrowing from 'loan sharks' is a survival strategy that was adopted by almost every household affected by HIV who participated in our research study. The families highlighted that they borrow money from 'loan sharks' since it was effortlessly accessible and easily obtained as opposed to formalised loans from banks and other legal lending institutions. Families reported that they have difficulties obtaining loans from the banks due to a lack of proper documentation needed (such as proof of residency, bank statements for three months, or proof of employment) and thus they 'would not qualify'.

Lawrence Mgcina (man, 59) is married to Nontobeko (woman, 43) and both are living with HIV. The couple were raising their two teenage children, Ikho (man, 13) and Lerato (woman, 18), and often spoke about how they struggled to make ends meet. Lawrence described how they opted for borrowing money when they ran out of funds:

> *We actually borrow money from the people that lend money out [loan sharks]. It's really bad borrowing money from them because if you borrow R100 from them you must put R50 more on top [add interest]. You see, they kill you [by demanding high interest rate].*

In this case, although the Mgcina family realised that the loan sharks are dangerous and expensive, they felt that they had little choice in the matter.

In the Jansen family, Nwabisa (woman, 29, living with HIV) lived with her partner Robert (man, HIV status undisclosed) in a one room shark as tenants at the backyard of an RDP dwelling. Robert worked as a part-time gardener while Nwabisa ran a business of selling (unlicensed) alcohol. As means to hide her HIV status from her husband and local community members, Nwabisa told how she collected her HIV treatment from a clinic located in another community. This required her to use transport to travel. Nwabisa explained to us that from time to time she would borrow taxi fare from loan sharks to go to the clinic.

> *Sometimes I would borrow money from these lenders [loan sharks.] Let's say, maybe when I'm going to the clinic to fetch my treatment [ARVs]. I don't want to go to this one here. So, it's better to borrow. I'd borrow R11 plus R15 and that is R26 [single] and R52 for return.*

In this regard, Nwabisa borrows money from loan sharks to attend to her health care as someone living with HIV. For her, attending a clinic appointment is important enough that she would borrow money from loan sharks to cover the costs related to her treatment.

In summary, borrowing from the loan sharks seems to negatively affect not only these families' current financial position, but their future budget as well. This means that many families are living in constant deficit, trying to catch-up to past loans while never being able to stretch their income to the next reliable source of income. Many families end up having to repay the loan from previous month with their next pay check or income source, and having to take out additional loans at the end of the month to survive.

4.2.3 Employment (formal and informal)

Families in our cohort also ‘get by’ through employment. Of the 15 participants living with HIV, 8 worked in the informal markets or were self-employed. Their employment can be described as mostly temporary or casual work. These jobs include the running of street vendor businesses, sex work, construction, or gardening work. Working conditions were often harsh with low wages. Moreover, these jobs were inconsistent and unreliable sources of income, which made it challenging for the affected families to manage their incomes properly and plan in advance.

For example, Thobela, a 39-year-old man living with HIV stayed with his two young-adult brothers, Thabiso and Ezile, in an RDP house. All of the siblings had temporary jobs, which meant that income for the household was unstable. Thobela, who previously worked at a construction company, described how temporary employment has affected him and how he felt he had to resign to search for another, more secure, job.

> *Researcher: Do they tell you how long you’re going to work there?*
>
> *Thobela: No, you work and work but then it depends. Because sometimes they [employers] say, ‘No don’t come to work. We haven’t got a [work] site yet’. And [then it] would take the whole week get paid, it also turns out to be a struggle. So, you’d end up getting your money while you sit and starve in the township with no pay ... things get annoying.*

Self-employment. When families struggle to find steady formal employment and reliable sources of income, they find other ways of surviving. Running an informal business such as selling food or products became one of the alternative prominent ways in which families adapted to generate income. This forms part of informal work which includes self-employment (Vearey, Richter, Núñez, *et al.*, 2011). Bongiwe (woman, 46, living with HIV), who also depended on social grants, was forced to quit her job as a helper for an elderly man to look after her sister's children. After resigning, she decided to supplement the disability grant money she received by selling 'braai' meat (meat cooked on an open fire) at an informal stand in front of her house.

> *Researcher:* *How did your business start?*
>
> *Bongiwe:* *The selling business? After I've quit that job of looking after an old man, I've been selling meat ever since. It's R350 to buy pork and the only profit I get is R150. Then I have to go buy more pork to sell again.*

In this instance, Bongiwe explained that although she worked hard to supplement the income, the profit margins were low and it was still a struggle to 'get by'.

Nontombi (woman, 43, living with HIV), who, as described above, worked as a sex worker to 'get by' has been the main breadwinner in her household. During one of our discussions, we asked Nontombi if she managed to generate any money during that specific week and she told us:

> *I got some clients that come here in the house. They phone me when they come and pay R150 which I spend for one or two days. Even yesterday I got R150. So that's why today I decided to sit here in the house and do cleaning. There are also two clients who called yesterday who said they'll come late today. But I don't know, sometimes they phone and say they'll come but they don't [arrive].*

However, even though Nontombi was able to generate her own income and support her household, the income was unpredictable and lead to uncertainty.

Households are vulnerable to the inconsistency of steady income and employment. The uncertainty surrounding jobs does not contribute to relieving financial burdens. For some, the fickleness of some forms of employment meant that they would rather give up available uncertain employment in the hopes of securing more stable employment or other forms of income.

4.2.4 Independent Survival Strategies

Another way which families affected by HIV survive is through independent and innovative or strategic ways of generating income. These independent strategies entail offering services or labour, and RDP house owners renting out backyard spaces to tenants.

Offering a self-labour service. I found that people would use their household assets or domestic labour skills as a service to generate income. These services overlap and could also be considered as a form of self-employment, but usually entailed more domestic duties, such as doing household chores for neighbours or taking care of children while parents or other caregivers are at work. Nolubabalo (woman, 42, living with HIV) who stayed with her two children Songezo (man, 17) and Olothando (woman, 12) as backyard tenants, supplemented her income through doing laundry for her neighbours. Nolubabalo used one of her few assets, her washing machine, as a way to leverage income in her community. When we asked her if her clients (neighbours) paid for the service, she said:

> *It's a must, it's non-negotiable. If he or she wants [their washing done] they must buy me a cool drink. I won't go to bed without food whereas there's something that can feed me [laughs]. Sometimes they just buy electricity. Maybe the other one will give me R30 or R50 depending on how good they feel [chuckles]. And a loaf of bread and half a dozen [eggs] is enough from that.*

In this account, Nolubabalo was offering a 'service' to 'get by'. The neighbours, which at this point were also her clients, supplemented her income not only by paying cash but also through providing other means of survival such as food and electricity. Therefore, it was not a fixed transaction or agreement, but the informal arrangement was based on the ability of the needs of the clients as well as Nolubabalo.

Renting out backyard space. To some people, the government-subsidised housing, known as RDPs, was more than just a house – it was a means to generate income. RDP houses are subsidised housing made of bricks fitted with circuited electricity and running water with enough space to qualify as a backyard. The RDP houses are built by the government and given to low-income families (National Department of housing settlements, 2018).

Households, including the Dalasile family, the Phaliso family and the Nofemele family, owned RDP houses and have resorted to renting out spaces in their backyards. The tenants, commonly known as backyard-dwellers, built their own one or two room shacks in the backyard and would connect to electricity in the main house through illegal and often unsafe extension cords. For instance, in the Dalasile household, Nomfundiso (woman, 45) lived in an RDP house with her younger brother, Lungani (man, 34) and sister, Khumbuza (woman, 29), all living with HIV. Nomfundiso had two tenants boarding in her backyard and each payed rent of R400 per month. Nomfundiso described the dynamics:

> *They [pay] rent every month end and then they go [and] they buy their own electricity. Their rent money is separated [not included] from electricity because they will say I misuse their money. So I give each of them a slip to go buy it [pre-paid electricity] themselves and punch it in the box [main household pre-paid electricity meter].*

The examples above show how families were using what was in their possession to leverage income. Even though these were not fixed incomes, they functioned as additional and independent strategies used for survival.

To conclude, this further shows that people have to balance needs and priorities to ensure survival for themselves, their families, and at times, for their neighbours. Living conditions are difficult for families affected by HIV and they are often forced to consider multiple ways to generate incomes. In the following section, I discuss how families in my study managed their various earned incomes.

4.3 The management of household incomes

In this section, I describe how families affected by HIV manage their incomes at the household level. To show how household incomes are managed, I first describe how incomes are organised and that is, how they are shared, pooled, or kept apart by household members. Secondly, I describe the power dynamics around income decision making at the household level. Lastly, I provide how household incomes are commonly spent by families. In understanding how incomes are managed, I am able to describe both the direct and indirect costs associated with HIV, ART access, and health care.

4.3.1 Organisation of incomes in households

In this study, the organisation of household incomes refers to different ways in which incomes are shared, pooled, grouped, or kept apart by families and family members. From my findings, I identified two prominent ways of how these families organised their incomes: through 'selective pooling' and individual survival.

Selective 'pooling'. I use the term 'selective pooling' to refer to the decisions of individual household members who group some of their incomes together, while also keeping money aside for themselves to spend at their own discretion (also see Schatz & Ogunmefun, 2007). This usually happens in the form of contributing certain pre-determined portions of incomes to cover selected shared expenses such as food, electricity, and rent. In some instances, this way of organising income involved dividing specific expenses among household members (Schatz & Ogunmefun, 2007).

Households such as the Mngxongo family, the Gobingca family and the Phaliso family manage their incomes this way. In the Mngxongo family, Xolisa is a community health worker (man, 52, living with HIV) staying with his wife, Nomawethu (living with HIV), an assistant nurse, and their two children, Asemahle (woman, 21) and Lihle (boy, 4) in their RDP house. Xolisa described how the couple divided their household expenses.

> *At home what I do involves paying clothing accounts and focus on children's expenses and their school things. Anything related to children depends on me. Groceries are handled by my wife. Electricity and rent are also paid by my wife.*

In this case, Xolisa and his wife divided their household costs amongst each other instead of contributing a set amount of money to cover common household expenses.

In other cases, people contribute pre-determined amounts into the household, while keeping money aside for their individual needs, such as health care. For instance, in the Jacobs family, Priscilla (woman, 45, living with HIV) stayed with her two daughters Arlene (25) and Yolanda (21), and her son Darren (13), while her husband Eddie (43, living with HIV) was no longer living with the family. Priscilla received a disability grant for living with diabetes and a child support grant for Darren, while Arlene and Yolanda were working at a fruit market. Priscilla described how they incorporated their incomes in the household.

> *You see these two [Arlene and Yolanda] are working and get paid every week. So, they give R200 every week and the money I get from social grants [disability and child support] I just use for other things that are missing [shortfalls] in the house. I also save some money for myself in case I get sick again, you know, as a person with HIV and diabetes.*

In our discussions, Priscilla mentioned that she would have random headaches and told us that she would reserve money aside to cover her health care costs while contributing portion of her social grant money to the household costs, like everyone else.

Individual survival. In some families, household members survived independently with minimum or no sharing of incomes with one another. Households such as the Donisi family, the Jansen family, and the Davidson family are examples of households that handled their incomes this way. For example, in the Davidson family, Dayson (man, 34, living with HIV), as mentioned above, stayed with his father Conrad (man, 70, living with HIV) and both men would 'get by' through receiving assistance from relatives, in addition to Conrad's old age pension grant. Dayson described how the two men operated for their own survival:

> *It's my father's all pay [refers to social grant]. It's his money, it isn't my money, and I don't care about his money. I support myself, I make sure that I don't go to bed without food. It's my fault if I don't eat. My father goes and borrows money for himself or sometimes would eat at his people [other relatives] where he normally goes. I don't worry about them.*

In this statement, Dayson explained that although he shared a home with his father, the two men did not share any responsibility for either acquiring resources or for ensuring survival of the other.

In the Donisi family, household members also managed their incomes this way, but in a slightly different manner. As described above, Cathline (woman, 51) stayed with her three adult sons, her teenage step daughter and her infant grandchild. Her two sons, Bongi (26) and Vuyo (28), worked as cashiers in the nearby supermarket and did not share their incomes with the rest of the family. Cathline received a disability grant for high blood pressure and acted as a caregiver for the rest of the household. When Cathline was asked what other additional support she received from other family members, she said:

> *No I don't have anyone who gives me the thingy [money]. Even my own sons [Bongi and Vuyo] who live here have their own children whom they support. It's the two of them who are working but they work for their own children. I hustle [work] for myself and my children.*

This shows that even though there are several household members who earn steady incomes, each person focused on supporting themselves and their own immediate dependents. In the section below, I describe how these families make decisions around their household incomes.

4.3.2 Power dynamics on income decision making

Decisions around income were often negotiated by members of the households, and in some instances, decisions were dominated by certain individuals. Power dynamics, characteristics of individuals including age, role in the household, and individual responsibilities shaped how incomes were decided in households. In this section, I describe decision-making with regards to income along the lines of two broad categories – matriarchal decision making and unstructured decision making. However, it is important to note that whoever gets to make decisions and how decisions are made in households are not stable and is subject to change over time.

Matriarchy. Many studies in South Africa have shown how domestic spaces were traditionally considered feminine spaces where women were associated with managing household tasks and in charge of nurturing and childcare duties (Helman & Ratele, 2016; Mfecane, 2016; Seymour-Smith & Wetherell, 2016). Men on the other hand were seen as the providers for their families (Helman & Ratele, 2016).

From our discussion with families, we found that women were often placed in charge of the financial management of their homes and held significant power over income decisions. The reasons for the power that women in my study yielded over financial decision could be ascribed to several factors. Firstly, as a result of absence of men in households, women were in positions (or at times forced) to make decisions around income and expenses. Secondly, many women were the main breadwinners in households as they engaged in both the formal and informal markets (see above). Thirdly, in some households, there was a mutual understanding between household members that men were expected to work and to provide for the family while women administered how incomes were distributed and used in the household. For these reasons, many households' decisions surrounding income were structured according to matriarchal systems[8]. This, of course, varied between households.

The Norman, the Cwethe, and the Nofemele families are examples of households where decision making on income was shaped along matriarchal lines. In the Norman family, Betty (woman, 33, living with HIV) stayed with her husband Peter (living with HIV), and their four teenaged children. Peter worked as a driver for a local company and the household income was supplemented by the child support grant for the children and Betty's physical disability grant. In our discussions with the family, Betty reported how she was responsible for managing all income sources, and was encouraged by her partner to use the money according to her own discretion. Below she explained how she makes decisions by herself in their household.

> *Look, it's just me who buys stuff. My husband is always busy. He draws the money for me before he leaves [for work or any errand] and gives me that R1500 that he gets paid every other week. Basically, he gives everything because there*

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[8] 'Matriarchal' refers to a family, society, community, or state governed by women. A form of social organisation in which the female is the head of the family (Helman & Ratele, 2016).

> *isn't any left to keep for himself. I'd only give him maybe R100 for petrol maybe. When his car needs petrol he'd say, 'Jesus, my car lights are dim'. Then I'd say, 'take this[R100] for you'.*

In this case, Betty seemed to dominate decision making and dictated what must be done with income, while Peter had to allude to his needs and negotiated when asking for a share of the income.

In some households, even though decisions on managing incomes were predominantly made by women, these decisions did not go uncontested or unquestioned. Nolubabalo (woman, 42, living with HIV) who stayed with her two teenaged children, Songezo and Olothando, received child support of R1000 every month from her ex-husband Fezile (living with HIV). Fezile had moved out of the house a year before our discussion with the household after a long dispute in their marriage. In the absence of Fezile, Nolubabalo had to take on the responsibility of making all decisions around expenses, although her decisions were constantly contested by her children. She reported that:

> *Songezo always says, 'daddy always give me R100 every 15th[of the month]' and he expects me to do the same. But I tell him 'daddy is no longer here. If I tell you I'll give you R50, that's going to last you for a week'. You see, their father, he would just take a wallet and put it there and say, 'here's the money'. So, they're up and down on the wallet. I am not like that.*

Although Nolubabalo had authority over their household incomes, she was continually being 'forced' into the position of decision maker because of circumstances. The position did not go unchallenged and it was difficult to maintain.

Unstructured. Some households were 'unstructured' in terms of decision making surrounding income. In such households, people made their own choices regarding spending with no one individual holding power over their decisions or the decisions of others and this meant that people still shared their incomes with others. The Jansen family, the Mgcina family, and the Dalasile family are examples of this type of household. For instance, in the Dalasile family, Khumbuza (woman, 29, living with HIV) was staying with her older sister Nomfundiso (45, living with HIV) and brother Lungani (living with HIV) in an RDP house. Lungani was the regular breadwinner at home, working as a seasonal construction worker while Khumbuza worked as a char once a week in a nearby affluent community. Nomfundiso generated income by occasionally taking care of or looking after her neighbours' children. When Khumbuza was asked how they decided on how incomes were spent, she said:

> *We don't decide [sit to discuss] but a person buys [items] that they see someone else wasn't able to get. I would do planning with my sister. My brother doesn't like talking about stuff in relation to his money. He just comes with that particular thing. He just buys. When he's about to get paid he just looks what's there and what's not there then when he comes back on Friday [from work] he brings things [for the household].*

Similarly, in the Mgcina family, Lawrence (man, 59, living with HIV) lived with his wife Nontobeko (woman, 43, living with HIV) and two teenage children, Ikho and Lerato. The family would 'get by' though the child support grant and assistance from their relatives, either in the form of cash or food. Everyone in the household decided on how their incomes were spent unimpededly, including the children. For example, in an interview with Lawrence and his wife about income and expenses, Lawrence said:

> *Look, it differs a lot. Not all the time Lerato gives her money [childcare grant] to us. She also uses the money when she needs something at school. We only fetch*

> *the money [withdraw] and give it to Lerato then she decides to give us some [pause] maybe when she doesn't have something to pay at school.*

The parents did not see the grant as their money, but rather as belonging to their daughter. She had the power to make decisions around her child grant money. In both these families, the Dalasile family and the Mgcina family, people decided on their incomes with no limitations on their choices. Below, I describe how the procured incomes were spent by many households in our study.

4.3.3 Households' priorities and common expenses

As described above, decisions around incomes are influenced by different factors at the household level. Expenses often changed in relation to different household composition and structures. Families highlighted different priorities when describing spending habits. The prominent expenses covered by many households with their incomes included basic needs; health care related costs; recreation (alcohol and drugs); and savings.

Basic needs. As expected, families affected by HIV, as with other households, spent a large proportion of their income on basic needs. The basic needs include both household and individual necessities. Household necessities comprise of groceries, electricity, and rent, while individual necessities include transport fees to work and school expenses.

Household necessities. People reported that basic survival needs, such as electricity, rent, and groceries were always necessary to be included on their budgets despite limited resources. For example, in the Norman family, Betty (33) was married to Peter and they were both living with HIV and raising their four teenage children. Betty described how she planned grocery shopping for her household:

> *Whenever I go buy food the meat price is high [on her budget] it likely cost R500. I then take the rest [remaining money] to go buy what I need most which is fish*

> *oil, rice and vegetables or something, but the food money is very little [not enough]. For real though, it's so expensive and look I even bought little food this month.*

In this case, it appears that due to limited resources, she had to purchase selected items of food that she deemed necessary.

In other households, such as the Cwethe family, members had to ensure expenses such as rent and electricity were paid in advance in order to secure a place of residence and remain connected to electricity. Nontombi (woman, 43) who worked as a sex worker stayed with her partner Zonke (woman, 28, living with HIV) in an informal housing unit they rented on a monthly basis. Nontombi explained the dynamics:

> *I was lucky over the weekend [that I had clients]. I managed to get money that I kept for rent because I know, on the first of March, I must pay rent. I don't want to fight with my landlord on the first so I must pay rent it's R350 [rent] and R150 for electricity for the whole month.*

Nontombi implied that paying rent and electricity to the landlord was important not only to secure a place to stay, but to avoid disputes she might have with the landlord regarding failure to pay.

Individual necessities. The basic individual needs include transport fee to work for those who are employed and school-related expenses for children. For instance, Cathline (woman, 51, living with HIV) has three sons, and was the caregiver of her grandchild and teenage stepdaughter. Cathline's youngest son, Kuhle (19), had, at the time, recently returned from initiation school. An initiation school is the traditional practice, in Xhosa called 'Ulwaluko', which is intended as a teaching institution to prepare young males for the responsibility of manhood (Mfecane, 2016). Initiation school is a cultural expense – but not one that can be ignored in Xhosa households. Cathline explained to us that their money had to be potentially earmarked for Kuhle's initiation costs, while they had to borrow money for his school afterwards.

> *There is a place that lends money out for people who receive social grant. I went to borrow a loan from there. I can take this one who's doing Grade 12 [Kuhle] back to school because I had to buy him books. I borrowed an amount of R1000 since he came back with new clothes of new men [from initiation school]. I had to buy him a uniform and new school trousers from the same R1000, you see.*

This shows that both Kuhle's initiation ceremony and his school expenses are regarded important and necessary in the household and Cathline had to borrow money to ensure that these costs were covered.

In summary, people faced several challenges and they had to make difficult decisions and balance different basic needs (individual or household) – often navigating which basic needs to cover.

HIV, ART and care costs. Only a few of the selected households affected by HIV, including the Mngxongo family, the Mgcina family, and the Dalasile family specified that allocated some portion of their incomes (money) specifically towards HIV care. In the Mgcina family, Lawrence and his wife Nontobeko (both living with HIV) were both unemployed and could mainly 'get by' through the child support grant from their teenaged children and interpersonal support from relatives. When the couple were asked if they have incurred any costs related to HIV care, Lawrence said:

> *I am the one who spends most money [on HIV care] because I got headaches [from taking ARVs]. So, every day, I must use pain tablets which are very*

> *expensive. I must specifically go and buy at least four to five packets of pain tablets or just buy Grandpa's and Disprin*[9] *every day that I use to eat [take] with ARVs.*

In this instance, a portion of the family income is redirected to indirect HIV care for Lawrence's pain tablets to ease the side effects (such as headache) attributed to his ARVs.

Similarly, Nomfundiso (woman, 45, living with HIV) stays with her brother Lungani (36, living with HIV), and sister and Khumbuza (29, living with HIV) in an RDP house in the Cape Winelands. Nomfundiso explained how her brother Lungani, who was the main source of income at the time, sacrificed the money he had to cover her health care costs:

> *I was diagnosed with HIV in 2003 but started treatment in 2011 [8 years after diagnosis] because whenever I ate, I'd just vomit and I lost energy. My brother [Lungani] was working at the supermarket back then and I said if tomorrow wasn't Saturday, I would be going to the[free] clinic. He insisted on giving me R200 to go to the [private] doctor. The doctor gave me medication to regain strength and referred me to the [local public] clinic.*

The family redirected the portion of income they had to ensure that she was able to access HIV-related care on a Saturday when the public health facilities would be closed. In this case, the health of the person living with HIV was deemed a priority and the household collectively decided to seek care for Nomfundiso.

Savings. Although households faced numerous challenges and money was scarce, 8 of the 13 families in the cohort insisted on consistently contributing to selected investments, such as saving money through a 'stokvel' system. Traditionally, a stokvel is a pooled savings

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[9] Grandpa (and Disprin) is a powder or a pill which contains a combination of paracetamol, aspirin, and caffeine used for the relief of pain (De Wet & Van Wyk, 2008).

scheme whereby members opt in to join a savings club or society, and each member would contribute a set amount of money every month (Haddad, 2004). Then, based on a predetermined rotation, each member would receive a lump sum pay-out at a specific time of the year. Betty (women, 33, living with HIV), who stayed with her four teenage children and husband described the dynamics:

> *We contribute R2000 to a stokvel. It's a give and take. Money is deposited in the bank and sent via your account when it's your turn to get the money. Then if you decide maybe they should extend it [pay it later] because maybe you want to buy something, they extend it.*

Similarly, Nontombi Jansen (woman, 29, living with HIV) stayed with her boyfriend Robert Mulawudzi (man, in mid-thirties) in a one room shack as tenants. Nwabisa runs an informal and unlicensed business selling alcohol while Robert works as a gardener. Nwabisa explained to us that she had joined a stokvel as a means to save her profits.

> *We are [part of a] stokvel. We contribute a lot per month and there's ten of us. I meet the target through business income. You see today is the 3rd [of February] tomorrow I'm contributing, and I already have it [the full amount] and today I counted it it's enough you see. We normally contribute to stokvel dividends around the 3rd [of the month].*

This pattern of managing and saving funds was commonly practiced by many families affected by HIV in the cohort, including the Norman family, the Mngxongo Family, the Cwethe family and the Phaliso family. In addition, these households would try and manage basic needs such as groceries and school expenses, and sometimes they would incur in debt, but still make sure they contribute to these savings.

Recreational activities. Some households in my study repeatedly mentioned that they use a substantial portion of their income on recreational activities, including buying alcohol or illicit drugs. Participants mentioned that consuming alcohol or using drugs helped them to distress, even if temporarily, while others described how they used these substances for pleasure.

For instance, in the Cwethe family, Nontombi (woman, 43) told the researchers that she drinks alcohol to cope with her circumstances. She explained that it was because she despised her job as a sex worker, but due to 'life struggles', and the need to support her daughter, she had to make 'sacrifices'. During one account, Nontombi explained how she drank alcohol to numb away the stress and the burden of working as a sex worker.

> *Researcher: What would you spend the rest of your money on?*
>
> *Nontombi: Tjo! [exclamation] I'm spending on food and I'm drinking also. You must understand that, and these past few days I'm drinking a lot. I'm stressed. My life alone is a disaster. I have no money and I'm stuck with a shitty job.*

In this case, Nontombi described that, although she also covered other expenses such as food, she ended up spending a large portion of income on alcohol to 'ease the 'pain' of working as a sex worker.

Thobela, a 39-year-old man living with HIV from a mixed metro site in Cape Town who stayed with his two young-adult brothers, explained how he prefers to buy and enjoy alcohol alone in 'peace':

> *If I buy a bottle of brandy and bring it to my house. I will slowly enjoy it the whole day till I go to sleep. I wake up in the morning [to work] and then I come back and drink my bottle and occasionally add some beers and then I'd go buy*

> *another bottle on Sunday. I can't drink with a lot of people. I sit by myself when I drink.*

In this case, Thobela claimed that he finds pleasure and preferred to be socially distanced from the company of others when he drank alcohol. Thobela's 'enjoyment' in using alcohol, alluded to alcohol dependency.

In the Davidson family, Dayson (man, 34, living with HIV) who lived with his father, Conrad (70, living with HIV) explained that he was recovering from long term and consistent drug use. Dayson was also diagnosed with TB. At one stage, he was found very weak and his family phoned the ambulance. He was admitted to a local TB hospital and we conducted an interview at the facility. During our discussions, we asked how he is coping, he said:

> *I started using tik [crystal myth] and buttons [Mandrax] again*[10]*. I'd smoke once or twice or three times a day. It made me fall back and it makes you to belittle yourself in front of people just to get to money [for drugs].*

Dayson described how he would beg for money in order to get access to drugs. Despite the struggles he had, addiction became an additional burden which is a cost that many households have to consider in addition to or in competition with meeting their basic needs.

Many participants, including Nontombi, Thobela and Dayson, engage in recreational activities such as drinking alcohol and using illicit drugs, but presented different reasons for doing so. Nontombi, claimed to be using alcohol as her coping mechanism from her troubling issues, whereas Thobela reported that he drinks alcohol to find pleasure but there are signs of escapism and alcohol dependency. Dayson claimed to beg for money with the motivation to buy drugs.

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[10] Tik (crystal myth) is an informal South African word used to refer to the drug methamphetamine, especially in powered crystalline form (Peltzer, Ramlagan, Johnson, *et al.*, 2010).

Households affected by HIV in the cohort manage their incomes in different ways determined by a variety of factors. As discussed above, households organized their incomes through selective ‘pooling’ and individual survival. These ways of organising incomes in households are influenced by power dynamics i.e. who has power over decision making around incomes. Matriarchy and unstructured became habitual power dynamics when it comes to income decision making in households.

The management of incomes is also linked to household composition and structure. Household composition is a description of the household according to certain characteristics of its membership, such as age, relationship to the head of the household, and number of marital pairs or nuclear families it contains (Smeeding & Weinberg, 2001). In this regard, people also managed incomes in relation to their responsibilities and roles, and on the basis of their priorities. In addition, many complexities such as how families ‘get by’ also influenced how they chose to spend their incomes. In the section that follows, I discuss how the management of household incomes affect ART adherence behaviour of people living with HIV.

4.4 ART adherence behaviour of PLHIV

In this section, I present how ‘getting by’ and managing incomes (as described above) impact on ART adherence experiences of PLHIV. I found that there is fluidity in how PLHIV adhere to treatment. Many PLHIV reported that, although they were inclined to initiate or adhere to ART, their treatment journeys would often be interrupted or delayed because of life circumstances.

Most PLHIV reported that, at some point, they were able to follow HIV treatment plans, take medication at prescribed times as recommended by a health care provider, and follow guidelines regarding food dietary and lifestyle (Azia *et al.*, 2016; Moosa *et al.*, 2019; Reda & Biadgilign, 2012). However, achieving ART adherence is complicated by a myriad of economic and social factors, including the use of additional supportive medication to manage the side-effects of ART, balancing ART treatment and work, eating sufficient food before taking pills, or the lack of transport fees to travel to the clinic in order to fulfil or renew ART prescriptions (Ahmed *et al.*, 2018; Steinert *et al.*, 2017; Young *et al.*, 2014a).

During my analysis, I found that PLHIV were supported in their adherence when (i) in their households income was managed according to 'selective pooling' and (ii) HIV care expenses were made a priority expenditure. This can be ascribed to the ability of PLHIV to maintain a balance between generating income (or going to work), accessing treatment, and in a few cases, where people were able to access additional (private) care.

'Selective pooling' and prioritising HIV care. Some families affected by HIV redirected a portion of their resources (money) towards the health care of PLHIV, despite financial constraints. For instance, as described above, Lawrence (59) and Nontobeko (43) are both living with HIV and had few resources, however, they prioritise health care and expenses surrounding ART adherence. The couple reported that they take their ARVs on a daily basis, but they had to put money aside to buy additional medicine such as pain tablets to ease the side effects (such as headache) Lawrence experienced. As mentioned above, taking additional medication to counter the side-effects of ARVs is part of ART adherence. Lawrence described the dynamics:

> *Since she took the medication, she never had any side effects. It's just me. I get headaches from taking ARVs. Every day I must drink two Grandpas [paracetamol] and pain tablets because without them I won't come right [be able to sleep]. She [Nontobeko] makes sure that I have them or I must specially go and buy them at the chemist.*

In this case, the family prioritised expenses like daily headache medication to ensure that Lawrence is able to adhere to his ART without experiencing side effects. Lawrence was only able to remain in care and take his HIV treatment on a daily basis with the support of additional medication. This also meant that, if the family had fewer funds available for additional medication, Lawrence's adherence to treatment could have been compromised.

There is a case similar to the experience of the Dalasile family. As noted above, Nomfundiso (45) stayed with her brother Lungani (36) and sister Khumbuza (29) and they are all living with HIV and reported that they were adhering to ART, as described by the health workers at the local clinic. Nomfundiso reported that her brother Lungani, who was the main income earner, offered financial help in order for her to access private care and to eventually initiate and stay on treatment. Below she described her experience on how she started treatment.

> *After I fell too sick my brother gave me money to go to a doctor [private care]. I was then sent [referred] to a local public clinic to start treatment there. Back then I was not in the [adherence] club but now every time I just arrive, I issue my card, climb the scale, and take my pills. I was told to eat them forever [take medication] so every day at 8pm I eat them [ARVs] but would fall asleep soon after.*

In this instance, Nomfundiso's health was deemed as a priority by her family which led her to initiate ART and ultimately engage in HIV care. Nomfundiso reported that she mostly took her treatment at the exact time since she started taking ART.

Going to work and accessing care. Maintaining a continued engagement and keeping appointments with health care providers frequently is a balancing act with other everyday priorities, such as employment. I found that, in these cases, people found alternative ways to ensure that their HIV treatment was collected from health facilities. Attending clinic appointments and collecting treatment was an essential component of ART adherence. For instance, in the Phaliso household, Bongiwe (48) would send her daughter Linda (19) or nephew Sibusiso (24) to go and collect her HIV treatment, allowing her to go to work, as a domestic worker and carer for an older man. When Bongiwe was asked how she remained on treatment, she said:

> *Sometimes I send Linda [to collect her HIV treatment] when maybe I am busy with a certain thing or when she is free with no schoolwork to do. Or sometimes I'd ask Sibusiso to pick them for me [pills]. For example, even during the time when I just started working.*

Bongiwe can be described as an adherent patient who prioritised her clinic appointments and collection of her HIV treatment despite other competing priorities such as having to go to work. As the main breadwinner, Bongiwe had to manage between going to work in order to provide for her family while she fetched her treatment through other means, such as sending her daughter or nephew to collect her ARVs from the clinic.

Access to private care. Most households could not afford private health care. The ones who accessed private care were mostly able to do so through employment benefits in selected occupations. Unexpectedly, the Gobingca, Mngxongo, and the Mgcina families previously relied on services like private medical aid to initiate HIV treatment. Affording medical aid through employment allowed these families access to HIV treatment prior to the changes in the national HIV treatment guidelines (2016) and outside of the PopART intervention when ART was not widely accessible to all PLHIV. Nontobeko (43) initiated HIV treatment shortly after diagnosis in 2004 (prior to the wider availability of HIV treatment). She was able to do this through her husband's medical aid, as he was employed as a police officer at the time. She explained:

> *I went for testing around August [2004] shortly before delivering [the baby]. I was waiting for medical aid since I didn't want to go to the [public] clinic. We went to see the [private] doctor, so we got treatment [Nontobeko and her husband] from the chemist [funded by medical aid]. But we stopped using medical aid because he's [the husband] is no longer employed but we still continued taking pills from the [public] clinic.*

Nontobeko explained that it would have been a challenge for her to initiate ART at the public health facility if she did not have access to a private health care as the treatment was not freely and readily accessible to PLHIV at the time. Nevertheless, Nontobeko managed to remain on care and still be adherent on ART despite not being able to access private care anymore. The means to access private health care facilitated the process of initiating HIV. treatment

Similarly, Nolubabalo Gobingca (42) stayed with her son Songezo (17) and daughter Olothando (12). Nolubabalo accessed private health care through the medical aid of her ex husband, Fezile. Nolubabalo described herself as an adherent patient who had been on ART even before the increased access to HIV testing and treatment. She reported that:

> *Even when I was pregnant with Olothando I was already on treatment using my husband's medical aid [to access care]. Doctors there [from the private hospital] ensured that they do rounds frequently [giving patient pills] especially us with HIV. Even now I'm still eating [taking] my pills [ARVs] because there's nothing I can do or change..*

In this regard, medical aid and the special support from private health care was key in the process of gaining access to treatment for Nolubabalo.

In households where resources were allocated to facilitate access and adherence to care, PLHIV were motivated to adhere to treatment. It should be noted that this also depended on the assistance of relatives or other household members. If these relatives were not able to provide their social support, the adherence or linkage to care of PLHIV could have been potentially compromised. The adherent patients often depended on other household members to ensure that they were able to access means of financial survival without compromising access to HIV treatment.

However, as life conditions change and different challenges emerge, people could move from being adherent to experiencing interruptions in their treatment journeys. PLHIV reported that, at times, they would miss doses, skip clinic appointments, discontinue engaging in health care or stop taking ART for a given period of time. Participant reported that factors such as competing household priorities, covering other basic needs, the need to generate income, and spending on recreation activities influenced their choice and their ability to adhere to ART.

Generating income but missing ART. Some people reported that they had to balance between attending health services and/or going to work, both which were deemed to be important in the well-being and survival of PLHIV. For instance, Thobela (39) who stayed with his two-young-adult brothers and financially support his extended relatives in the Eastern Cape, would sometimes skip clinic appointments to go to work as a road construction worker. Below he explained:

> *I was in the Eastern Cape for six months. I don't remember the year, but I think it was 2014. I took them [ART pills] very badly [infrequently] because when I came*

> *back I quickly got a job where Bongile [friend] works. I didn't have time [to attend the clinic] and at some point, I took my [clinic] card and sent children [to fetch the tablets] but they said [at the clinic] I must go there myself.*

Thobela described that he wanted to access treatment and tried to come up with alternative arrangements to pick up his medication. However, his work as a road construction worker and the responsibility of taking care of the financial well-being of his household was the first priority. Although other PLHIV, including Bongiwe (described above) were able to negotiate treatment access through relatives (children picking up treatment), this was still a challenge for many others, including Thobela. For many people on minimum wage or informal employment positions, there was very little flexibility and taking leave could compromise their much needed employment.

Recreational activities interrupting adherence. From the data, I found that recreational activities such as buying and drinking alcohol acted as a barrier to the prescribed use of ART. Participants in the study reported that they did not necessarily choose resources for alcohol over the use of resources to secure ART (or health-related costs), which would qualify them as direct competing priorities. Instead, people would decide to spend money or resources on alcohol which in turn and indirectly adversely influenced their ART adherence behaviours, including missing doses while engaged in recreational activities.

Nolubabalo (42,) explained to us how her ex-husband, Fezile (living with HIV), would miss prescribed times of taking his ARVs when he consumed alcohol. Afterwards, he would try to 'catch-up' on missed tablets:

> *He would drink the whole weekend non-stop. And then on Sunday he'd stop [drinking alcohol] at three o'clock and sleep. Around six o'clock he wants to take medication [for the days he missed]. He would eat pills [take ART] three times in one day and he wouldn't want me to say 'no' and I would be like 'okay let's not*

> *fight, it's your medication anyway'. But it's overdose you see, because he's taking a lot [of pills] in a short time frame.*

Fezile, would not only miss dosage at prescribed times as recommended, but also fail to comply with the guidelines of maintaining a 'healthy lifestyle' while on ART (Kalichman *et al.*, 2012).As was shown in the findings above, many households assigned a substantial proportion of their income on these recreational activities which potentially compromised their adherence to HIV treatment.

Basic needs over ART. PLHIV also faced financial hardships due to health-related costs such as buying additional medication to balance the effect of ART, income lost due to time spent seeking care, and transport costs to clinics. Costs related to HIV care, at times, could not be met when resources were assigned to other necessities such as food, electricity, and school expenses. For example, in the Phaliso household, Bongiwe explained that her daughter Linda (19) could not consistently adhere to HIV treatment due to the financial burden of indirect costs.

> *We went to fetch her [Linda's] treatment [from the clinic]. Her medication goes hand-in-hand with aqueous cream and tubes for her skin with spots. The problem with the clinic is that they run out of stock and they tell us to go buy it at the chemist. How am I supposed to get money to buy that treatment? It's so expensive yet it's free there [at the clinic] but they're making business out of it [insinuates corruption]. I don't have money. The money is finished on food and on her school stuff.*

In this case, as in other cases, treatment adherence is about more than just taking pills. There are multiple factors that are part of the process of taking ART, including the availability of treatment in clinics, buying and using additional medication to manage ART side-effects, and interpersonal support. Structural challenges (poor public health services) also affected Linda's health, and as a result of lack of financial means and other competing priorities coexisting in the household, Bongiwe could not buy her daughter additional supporting medication needed to fulfil her daughter's ART adherence.

Some PLHIV reported that, at first, they were reluctant to initiate treatment despite being aware of their HIV status. During our discussions with them, they told us that, for reasons including the use of alcohol or drugs and being depressed, it became difficult to start treatment. Below, I describe how the use of alcohol or drugs had an impact on the adherence behaviours of PLHIV.

Recreational activities delaying adherence. I found that many PLHIV who devoted funds to substances failed to initiate or delayed ART initiation. For instance, in the Davidson household, both Dayson (34) and Conrad (71) described how they would spend most of their income on illicit drugs before they started treatment. As mentioned earlier, these men depended on interpersonal support and old age pension grant for income. Dayson explained how because of prioritising spending on drugs, he delayed ART initiation for two years, since his HIV diagnosis in 2012:

> *Drugs did that man. When you start using drugs then you don't worry about medication anymore. It's just drugs drugs drugs. I didn't worry about that [medication] and I wasn't on the pill [ARVs] for so long. They just don't work with medication. Every [bit of] money you get you spend on drugs and ignore everything including medication*

For Dayson, available resources were largely organised and directed towards illicit drugs, while HIV care or ART was not mentioned as a priority for him. This includes spending money on other things that would make it easier to take ART, such as medication for side effects or food to eat before taking ART.

For the Cwethe family, decision making around incomes and spending was done in a democratic fashion and collective way (Belch & Willis, 2002). Both Nontombi (43) and Zonke (28) decided how to spend income even though Nontombi, a sex worker, was the main breadwinner at the time. The couple would direct a substantial portion of their resources to alcohol. At the time of the interview, Zonke said she had not started ART and used alcohol as a temporary relief from the stress of everyday life, including the knowledge that she is living with HIV. She reported that:

> *We just buy alcohol and drink. We drink mostly here in the house or the house next door in the shebeen [unlicensed local tavern]. She drinks more than me though [Nontombi] but this thing won't help me you know. I will drink and get drunk now; tomorrow the stress is still there you see? Because I'm getting sicker, but haven't taken treatment yet.*

Zonke acknowledged that she was neglecting her health and that alcohol was not a solution or a substitute for HIV treatment. In this regard, Zonke also admitted that alcohol was the main barrier to taking ART. For both of these families - their spending habits destabilized the process of initiating their ART and health care.

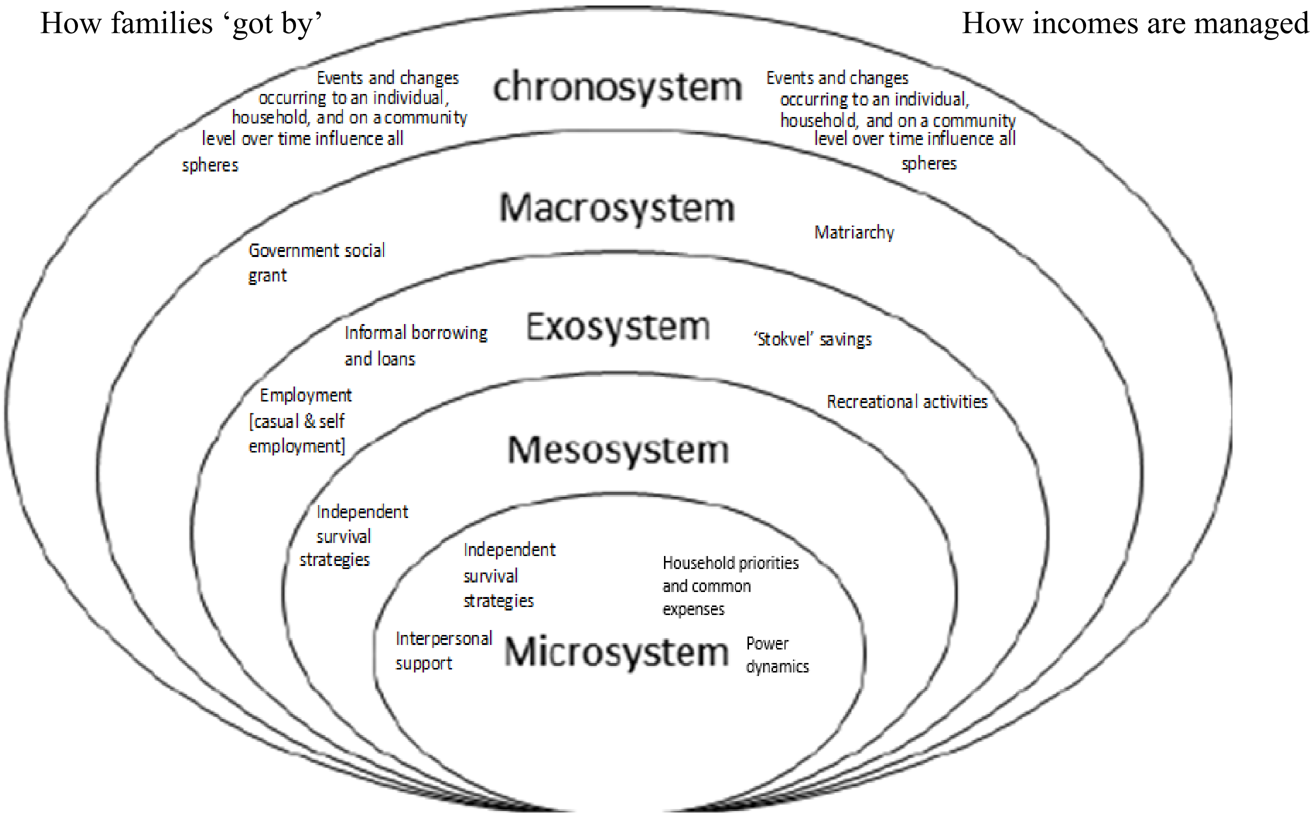
In this section, I described the fluidity of the choices made by PLHIV towards adherence. Changeability of the management of household recourses, including decision making on incomes and expenditure patterns influenced these choices. I have shown that families that decided to reserve money aside for HIV care and prioritized health, potentially influenced PLHIV to seek and to remain on care. However, other households that redirected (and not necessarily or entirely prioritized) some portion of incomes on substances, ultimately intercepted or prevented PLHIV from being adherent to HIV treatment. Moreover, household dynamics such as how PLHIV and their families ‘get by’, the responsibilities and roles, such as the need to work and provide for their families also made an impact on their ART adherence behaviours.

Chapter 5: Discussion

5.1 Interpreting findings

In this chapter, I use Bronfenbrenner’s theoretical framework to interpret the findings from my study. First, I contextualise ways families ‘got by’ and managed their incomes using the five layers of Bronfenbrenner’s theory (see Figure 4 below). Thereafter, I show how factors located in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem affect ART adherence behaviour of PLHIV. I show that these systems interact with one another, and they all have influence on the microsystem. In the discussion, I engage with the literature to show how existing studies support, contradict, or compare to the findings presented in this study.

Figure 4: *How families ‘got by’ & how incomes are managed*



spaces in their RDP backyards as other means to secure additional income. When households ran out of resources, people reported that they would opt to borrow money from the ‘loan sharks' in their neighbourhood. This way of 'getting by' falls under exosystem as these families borrows from community members who do not form part of their inner circles, but live amongst them in their neighbourhoods. At the exosystem level, I also found that people 'got by' through employment, and even though their employment was unreliable, they managed to cover certain expenses they considered as a priority over others. These incomes were supplemented at the macrosystem when the government provided social grants including child support, disability, and old age pension grant. Furthermore, how families 'got by' was influenced by historical events, changes in environment, and life transitions that occurred over time, which falls under chronosystem. For instance, some participants reported that at some point in their lives, they would lose their main source of income such as employment due to instability of working days, or at times, they had to leave their jobs to be caregivers of their relatives (see section 4.1.2). At such times, people had to consider alternative ways to secure incomes including independent survival strategies or running informal businesses.

How incomes were managed was influenced by factors located at different levels of Bronfenbrenner's ecological systems, although it mostly took place at the household level, which is the immediate operating environment of a person. As described in Chapter 4, the management of household incomes includes how household members organise incomes, how decision making around incomes was structured, the different household priorities and expenditure patterns. The way incomes were managed in households was influenced by other factors located beyond the immediate environment. For instance, at the level of exosystem, securing resources for recreational activities were severely influenced by broader social aspects associated with the stress of undesirable workplace (see section 4.2), and at times, the knowledge of being diagnosed with HIV, at an individual level. In addition, many families in my study were living in resource-constrained settings where incomes are generally low.

Many households lacked adequate resources to make ends meet on a daily basis. As a result, many households had to alter their expenditure patterns, including the need of having to prioritise certain expenses over others for survival.

5.2 Analysis of ART adherence behaviours: using Bronfenbrenner's theory.

In this section, I present the adherence behaviours of PLHIV against Bronfenbrenner's systems theory. I show how factors located in all five systems (see figure 1) are interrelated and interconnected, and how they have both a direct and indirect impact on the adherence behaviours of PLHIV.

Microsystem

In my study, I found that PLHIV could potentially be adherent to ART when there is strong interpersonal support, there is selective 'pooling' of household resources where HIV care expenses are prioritised. I found that factors that fall within the microsystem have the greatest impact on ART adherence behaviour of PLHIV. The microsystem is the immediate environment where a person exists in relation to family, peers, church, or school. It is here that attachments and strong bonds are formed, a secure based realised, and identity is moulded (Bronfenbrenner, 1979).

I found that in families where decision making was unstructured, choices around incomes were unimpeded and people organised their incomes through selective 'pooling' and according to their own discretion. In selective pooling, people would contribute a certain amount of money to cover household expenses while putting money aside to cover their personal needs, including health and care related costs. In few cases, people would make an exception to borrow money from loan sharks to cover expenses related to seeking care, including borrowing money for transport to visit the clinic (see section 4.2.2). At times, people would decide to prioritize expenses surrounding ART adherence through reserving resources to secure additional medication such as pain tablets to counter the side effects associated with taking ARVs.

A study by Nagata *et al.*, (2012) in sub-Saharan Africa, found that there is a strong correlation between ART side effects and non-adherence. In their study, they found that many participants who could not afford basic nutrition or additional medication encountered unpleasant side effects of ART and were often unable to adhere to treatment (Nagata *et al.*, 2012). Therefore, it is important for households to decide on incomes in a manner that facilitates the health care needs of PLHIV in order to enhance their optimal adherence to care. In my study, I found that many PLHIV faced challenges with ART adherence. However, households had the potential to minimise these problems by creating a health-enabling environment for PLHIV through offering social support and through creating an economic environment where ART adherence is prioritised and supported (also see Masquillier *et al.*, 2016)

In this study, I intended to assess how the management of incomes affected ART adherence of PLHIV. I found that the way families ‘got by’ also had an impact on adherence behaviours of PLHIV. For instance, interpersonal support was reported to be a facilitating factor in encouraging people to be adherent to ART. Social support includes encouragement from family, neighbours, and friends to co-operate with the prescriptions of health professionals (Masquillier *et al.*, 2016). At the level of the microsystem, interpersonal support can be shown in many ways from various sources including the provider-patient relationship, family, peers and immediate social networks within a community (Masquillier *et al.*, 2015).

I found that in times of financial hardships, social support strengthened optimal adherence to care through providing financial and tangible resources for PLHIV, including food to take with medication or transport fees to attend clinic appointments. In other cases, families were proactive and received food parcels, money, or other forms of resources in exchange for their labour services, including doing domestic chores for neighbours. A systematic review by Wadell and Messeri (2006) focusing on social support, disclosure, and the use of ART showed similar results when participants from various studies that were reviewed reported that their neighbours and relatives supported their adherence by giving them resources such as food to eat before taking ART.

While interpersonal support and prioritizing health facilitated optimal adherence to care, there were coexisting dynamics involved in the microsystem, including competing priorities, which interrupted treatment for many PLHIV. As described in Chapter 4, priorities were different between households. These differences altered expenditure patterns, and in turn, the ART adherence behaviour. Many households had competing economic priorities and participants who reported that they interrupted their treatment at times were prone to highlight these competing priorities as a contributing factor to treatment interruption.

At times, costs related to HIV care could not be met when resources were allocated to other household necessities such as rent, school fees, groceries, or electricity. Many households consistently lived with deficient resources and were often forced to choose between covering HIV care costs or other basic needs, both which can be deemed important in the livelihoods of PLHIV. When other household needs were regarded more important than expenses related to ART adherence, PLHIV suffered the consequences of treatment interruptions.

In sub-Saharan Africa, it is well documented that a lack of resources has adverse effects on ART adherence (Azia *et al.*, 2016; Kagee *et al.*, 2011; Nagata *et al.*, 2012). Lack of resources often result in food insecurity and insufficient funds for transport fees to attend clinic appointments (Steinert *et al.*, 2017; Young *et al.*, 2014b). A number of studies found that food insecurity in low income settings affected the regularity of ART doses as patients reported to take their medication only when there was access to food (Nagata *et al.*, 2012; Weiser *et al.*, 2010; Young *et al.*, 2014b). However, in my study, food insecurity was not explicitly mentioned as a barrier to ART adherence. Instead, participants explicitly reported that, at times, they would allocate recources to cover basic needs (including food) over health care related expenses when resources in their households were inadequate.

In some households physiological needs coexisted with recreational activities. However, allocating resources to recreational activities was not an explicit decision to prioritise ‘fun’ over ‘health’ or over ‘basic needs’. Rather, recreational expenses compromised adherence as an indirect consequence of substance use. People that reserved a portion of incomes to buy alcohol experienced poorer ART adherence, as they reported to have missed pill doses when engaged in these activities. The influence of recreational activities are also nested in the broader community level as many households in resource-constrained settings, including households affected by HIV were reported as being ‘subjected to alcohol abuse’ (see Kalichman *et al.,* 2012). This would mean that the use of alcohol or drugs cannot be limited to the microsystem but should be linked to broader macrosystem and exosystem as well.

A publication by Kalichman *et al.*, (2012) on alcohol use and ART adherence in South Africa found that, engaging in behaviours such as alcohol consumption would either delay or interrupt treatment adherence. In their findings, Kalichman and colleagues described how alcohol consumption did not only interrupt ART adherence, but was also associated with risky sexual behaviours and exposure to HIV transmission (Kalichman *et al.*, 2012). In addition, earlier studies found that the use of substances interfered with ART use, not only by affecting adherence to regimen, but also furthering HIV progression in one’s body (Chander, Lau & Moore, 2006; Parsons & Mustanski, 2006; Samet, Cheng, Libman, *et al.*, 2007).

Health practitioners are aware of these associations and often advise their clients about the risks associated with the use of substances while enrolled in HIV care (Adeniyi *et al.*, 2018; Parsons & Mustanski, 2006). In this study, PLHIV also reported that, at some point, they were aware of their HIV status but delayed initiating care because of the use of substances. For some PLHIV, recreational activities became a physiological need; they reported that drinking alcohol or use of drugs brought a temporary relief from the stress of everyday life, including the knowledge of being diagnosed with HIV. For this reason, people stated that they would organise and redirect large portion of household resources towards illicit drugs or alcohol, ignoring expenses surrounding ART.

In addition, studies located in low income settings have found that the presence of one person living with HIV in a household resulted in changes in expenditure patterns (Kibret, 2018; Merten *et al.*, 2010; Sharma *et al.*, 2015). For instance, a study by Merten *et al.*, (2016), found that supporting ART adherence of a relative means investing valuable time, energy, and at some point, redirecting financial resources into a single individual. Furthermore, the care of and loss of family members living with HIV translate into losses of household income through higher medical and funeral expenses (Steinert *et al.*, 2017). However, in my study, expenditure patterns were altered because PLHIV redirected household resources to secure and use substances with the intent, as some noted, to escape the knowledge of being diagnosed with HIV.

Exosystem

I found that there were external factors that operated beyond the microsystem, which directly and indirectly affected the adherence behaviors of PLHIV. These external factors are found at the exosystem and had a major influence on the microsystem. The exosystem is distant to the subject and often takes on an institutional form. This would include social services, health care systems, mass media and employment (Bronfenbrenner, 1971).

Factors identified in this study that fall within the exosphere emerged as competing priorities including the need to balance between engaging in health care services and/or going to work, both which are deemed important to the survival and well-being of PLHIV. As described in Chapter 4, people have to balance their needs and priorities to ensure survival for themselves, their families, and at times, for their neighbours (also see Kibret, 2018; Steinert *et al.*, 2017). Some people reported that they 'got by' through working in the informal markets which were unreliable sources of incomes. Many people described that they only had access to informal employment where there is very limited flexibility and taking a leave to access health care could potentially compromise their employment. For this reason, many PLHIV were interrupted from treatment as they would miss clinic appointments at times due to the need to secure means of employment.

An earlier study by Kagee *et al*., (2011) on the structural barriers to ART adherence in Southern Africa showed that frequent absences from work by PLHIV created conditions under which employers may terminate employment if they are unaware of the reason for such absences. In my study, that was a concerning challenge for many PLHIV at the exosystem level as attending health care services placed additional economic strains on patients and their families by competing with income generating activities. In the attempt to address this challenge, PLHIV would resort to send relatives or friends to collect HIV treatment on their behalf. However, these attempts were often unsuccessful as (outside of adherence clubs) the health care facilities required the physical presence of a patient. In this regards, one can conclude that the health care system, in addition to competing priorities, imposed a potential barrier that interrupted adherence of PLHIV.

However, there were few cases where relatives or friends were able to access treatment in health facilities on behalf of PLHIV. This created a platform for few others to manage being adherent since they could access treatment through the help of relatives while at work.

Moreover, prior to the changes in the national HIV treatment guidelines in 2016 which proposed “treatment for all”, many PLHIV in my study could not access care immediately after diagnosis (Adam & Johnson, 2009; Simelela & Venter, 2014). The few who did, were able to do so usingmedical aid as part of their employment benefits. PLHIV who could access private care prior to universal access to ART described how they would not have been able to start ART if they went to public health facilities. For this reason, for some individuals, employment was key in strengthening optimal adherence to care through medical aid schemes.

Although it was not explicitly evident from the findings in my study, a number of studies found that PLHIV who were breadwinners and had not started ART, would rather use their strength to earn an income and continue providing for their families while feeling healthy, than go for treatment (Ahmed *et al.*, 2018; Kibret, 2018; Steinert *et al.*, 2017). This behaviour created an environment where PLHIV were delayed from initiating treatment, which resulted into exposure to opportunistic infections and HIV transmission (Letta, Demissie, Oljira, *et al.*, 2015). This could undermine the efforts of wider implementation of “universal test” and “treat-for-all” including the effectiveness of TasP. As also anticipated by Hayes *et al.*, (2011: 2) “achieving high coverage of ART in resources constrained settings will become increasingly difficult” due to socioeconomic barriers. A publication by Orne-Gliemann *et al.*, (2015) which drew results from the ANRS project that evaluated TasP in Kwa-Zulu Natal, showed that receiving ART immediately after diagnosis became challenging for PLHIV who “did not feel sick” and thus did not regard HIV care as a priority. In my study, there is a similar case where people, in addition to the use of illicit drugs, were reluctant to seek care, relating how they had not experienced any HIV related symptoms at the time.

Macrosystem

Competing priorities between work and accessing care is associated with other complex factors that operate within, and at times, beyond the exosystem. Public beliefs, cultural values, and political ideologies were also involved in shaping ART adherence behaviours of PLHIV. It is against this background that social and political policy are formed. These factors fall within what Bronfenbrenner (1979) identified as macrosystem. The macrosystem focuses on how cultural elements at a larger scale including socioeconomic status, wealth, poverty, and ethnicity affects a person's development and health behaviour.

The macrosystem is the umbrella influence of what transpires in the preceeding layers of Bronfenbrenner's ecological framework, including factors located in the exosystem, mesosystem, and microsystem. The influence of broader social, economic, and political aspects trickle down from the community to the household level, and ultimately, to the individual. For instance, South Africa is known to be amongst the countries affected by poverty, economic challenges, inequality, and poor health system (Kagee *et al.*, 2011; Negin *et al.*, 2017). Families affected by HIV in my study were living in resource-constrained settings where many households had very low incomes and had access to health systems experiencing challenges. Low incomes which result in a lack of resources in households meant that many families were forced to choose between covering expenses surrounding ART adherence or other basic household needs such as school expenses, food and electricity. Although this challenge is found at the household level, it is important to acknowledge that macro aspects, including health inequality, lack of job security, and financial support for families affected by HIV were key drivers of these challenges.

In addition, before treatment became widely available and accessible to all PLHIV, many people in my study reported that they had difficulty in accessing HIV treatment. The public health policies, within and beyond the country, offered HIV treatment to few individuals who were eligible according to treatment guidelines. However, even after treatment for all PLHIV was introduced in the country in 2016, many PLHIV were still experiencing interruptions accessing ART care due to household poverty, a lack of resources to secure additional medication to counter side effects of ARVs, and transport fees to go the clinic.

Chronosystem

The challenges, as described above, are also immersed to the chronosystem; the last layer of Bronfenbrenner's ecological framework. The chronosystem is the time-based dimension that can alter the operation of microsystem, mesosystem, exosystem and macrosystem. At the chronosystem, the behaviour of an individual is shaped by events, immerging circumstances, and changes in the environment they live in, all which occur over time (Houston, 2015). These changes may also include factors such as mobility, change in public policy, and culture or tradition, which ultimately influence the behaviour of an individual.

In my study, the adherence behaviour and well-being of PLHIV were also affected by both current and historical events they experienced throughout their lifetimes. I found that the environmental changes that occurred overtime including major transitions and changes in the national HIV treatment guidelines had an impact on ART adherence behaviour of PLHIV. Households selected in my study were located in communities where the HPTN 071 (PopART) trial delivered an HIV combination package and UTT at the household level prior to changes in the national guidelines. Results of the PopART trial showed new infections were 20% lower in communities (located in arm A and arm B) where increased access to HIV testing and treatment opportunities was introduced along with other prevention measures compared to communities that received standard of care (Hayes *et al.*, 2019). In addition to other household factors that encouraged ART adherence, many families in my study reported that free access to ART strengthened their optimal adherence to care. However, other concurrent events that were taking place throughout the courses of their lives, including losing employment and engaging in recreational activities, remained intact. For instance, several participants reported that their employment was unstable and they would often change jobs, therefore, whenever they are employed they would rather go to work to secure stability than attending clinic appointments.

5.3 Strengths and limitations

The main strength of this study is that I had access to the large PopART social science database and I was able to draw on detailed, longitudinal, and ethnographic data that was suitable for my study. The data enabled me to do a detailed exploration of household income impact on ART adherence beyond once-off interviews with participants. The data I used was collected by well-trained social science researchers from various backgrounds and knowledge which minimised the limitations of data collected from the perspective of a single researcher (Kelly, 2006a). Data collection included various methodologies involving interviewing, ethnographic observations, and interactive discussions that included activities. The data was based on sampling for diversity and included the use of multiple data entities including recordings, fieldwork notes and verbatim transcripts. Therefore, the quality of the data supported the means to do a detailed, systematic analysis for my study which is imperative for qualitative research (Terre Blanche *et al.*, 2006).

There is currently limited research on the assessment of expenditure patterns in household affected by HIV in relation to HIV treatment (Bachmann & Booysen, 2003; Booysen *et al.*, 2003; Oni *et al.*, 2002). Accordingly, my study addresses a gap in that it did not only explore expenditure patterns, but also addressed the impact of the management of incomes on ART adherence behaviour of PLHIV in the Western Cape, and, more particularly, in the context of UTT.

However, there were some limitations. The sample size for my study was small, appropriate for a qualitative study, but still may be a limiting factor generalisability of study results to other communities. Further, the study focused only in households located in PopART intervention communities where ‘universal test and treat’ was implemented prior to changes in the national HIV treatment guidelines (NDOH, 2016). We still do not know how the management of incomes impact on ART adherence behaviour in comparison to PLHIV in communities where standard of care was delivered.

In addition, I was not part of the team that developed and designed the PopART study methodological framework, including sampling and research questions used to collect data and the study results were drawn from retrospective analysis of secondary data collected for another purpose. However, I was involved in collecting some of the data and actively participated in the transcriptions and translations of recorded interviews.

Furthermore, I analysed data including translated transcripts from IsiXhosa or Afrikaans to English and some of the meaning or complex qualities of the data may have been lost in the process of translation. However, with the help of peers, I was able to go back and listen to the audio recordings when uncertain about a particular text. Also, the translation was verbatim with background information included in transcripts which eliminated almost all the glitches on data.

5.4 Recommendations and potential ways for future studies

In order to make recommendations for future policy and practices based on the findings of this study, it is useful to review factors that strengthened optimal adherence to care, the causes of treatment interruptions, and what transpired to reluctance in treatment initiation. Factors identified in this study that strengthened ART adherence, included: (1) allocating household resources that facilitate ART adherence, (2) the ability of households to prioritize HIV care expenses, (3) the ability of PLHIV to balance going to work and make alternative arrangements to collect pills, (4) and access to private care. Participants emphasised competing priorities as contributing to treatment disrupting. This included the tensions between: (1) going to work and attending clinic appointments, (2) basic needs over ART, and (3) drug use or alcohol consumption over taking treatment. Participants who said that they were reluctant to initiate ART highlighted recreational activities and the stress of living with HIV as underlying factors for non-adherence. Below, I provide recommendations on steps that can be taken to support adherence to ART and ways that could minimise factors associated with breaks in treatment adherence.

- First, it would be important for government organisations to ensure that public health systems are better set up to respond to the needs of clients. For instance, during COVID-19, extreme measures were implemented to ensure the good health of citizens. This included turning community facilities into temporary hospitals for quarantine, mobile clinics for COVID-19 testing were deployed, educational campaigns were made standard, safety measures were put in place to contain the pandemic (Reddy, Sewpaul, Mabaso, *et al.*, 2020). Similarly, additional steps can be taken to support and improve ART adherence. For instance, health departments could consider establishing treatment delivery services, provide a registered 'treatment buddy' pick-up service and/or a mobile (phone/application) service as a reminder of clinic appointments.
- Secondly, many families affected by HIV reported that it is challenging to redirect household resources to cover ART related expenses as they face financial hardships and lack resources. Therefore, it would be useful for government to intervene by providing financial support to households affected by HIV through relief funds or a 'treatment-support-grant' (Nattrass, 2006). This can be administered through the clinics, when clients collect their HIV treatment. The government already provide other grants including child support, disability and the old age pension grant and many families in my study described them as useful in their

survival and livelihoods. However, the social support grants currently administered by the government are not HIV-specific and cannot be relied upon to help improve adherence to treatment. These HIV-specific grants can help elevate household incomes so there would be no need for competing priorities.

- HIV treatment packages could include food parcels, transportation fees, and additional medication to counter side effects associated with ART. Providing a treatment package with parcels encouraging ART adherence could potentially limit treatment interruptions associated with food insecurity, ART side effects, and the concern of having to choose between covering HIV related expenses or other basic household necessities.
- Third, the government can promote standard policies that would allow PLHIV opportunities to attend clinic appointments without the fear or risk of compromising their employment when absent from work. Government policies could suggest that companies offering informal work and temporary employment must consider amending policies that offer special sick leave for any urgent HIV related matter, including attending clinic appointments, without issuing threat or non-payment for an individual's absenteeism.
- Fourth, many PLHIV reported that their physical presence is mandatorily required by the nurses for clinic appointments. Alternatively, the public health policies around ART collection could be made flexible, where arrangements of accessibility are made. For instance, give permission for relatives, friends and family members to be able fetch treatment in the absence of PLHIV. This could help reduce the problem oriented to the balancing act of going to work or accessing health care.
- Fifth, it would be important be important for NGOs, public health sector, and health interventions to conduct door-to-door awareness campaigns that teaches about the importance of allocating resources that cover expenses surrounding ART adherence. This could also help

curb HIV stigma as many families would be brought into understanding about the importance of their interpersonal support towards PLHIV.

- Sixth, many PLHIV faced problems associated with ART adherence, but households and neighbourhood have a potential to minimise these problems by creating a health-enabling environment for PLHIV such as offering interpersonal support (also see Masquillier *et al.*, 2016). The interpersonal support could include the provision of financial or tangible resources such as food to eat before taking ARVs. Additionally, adherence clubs and community support groups including Treatment Action Campaigns, Soul City Institute, and LoveLife already exist, but more are needed. The investments from the government to finance the expansion of these community support groups and adherence clubs could be beneficial in improving ART adherence.
- Lastly, many families that reserve resources for recreational activities need to be targeted with specific campaigns or interventions focused on the health risks associated with using substances while enrolled on HIV treatment. In this way, we would be able to prevent PLHIV from skipping treatment when engaged in recreational activities including drinking alcohol or using drugs.

From the recommendations presented above, we can learn that there is no singular strategy that can be used to strengthen ART adherence. In order to ensure optimal adherence to care, it is useful for health interventions to develop multiple context-specific strategies that are suitable to address challenges associated with interrupted adherence per setting. Moreover, it is important to consider the myriad of factors that are located outside the micro sphere as their influence trickle down from a broader level to the individual level. Nevertheless, as similarly shown by Sharma and colleagues (2015), my findings further convey that households with PLHIV need much greater support in terms of accessibility and affordability of health care to avoid household economic catastrophe and competing priorities between health and other necessities. Below I expand on this proposition.

5.5 Conclusion

As discussed in chapter 1, the aim of this study was to explore how the management of incomes impact on ART adherence behaviour of PLHIV in the Western Cape province. To begin with, I described how families affected by HIV 'got by'. I found that living conditions were difficult for families affected by HIV as they faced financial hardships and were forced to employ various strategies to make ends meet. People had to balance needs and priorities to ensure survival for themselves and their families, and at times, for their neighbours.

The way families 'got by' had a substantial impact on their household expenditure patterns, and in turn, on ART adherence behaviours for PLHIV. Some households affected by HIV had to adjust their expenditure patterns to ensure support for PLHIV. Supporting the ART adherence of a relative or a family member meant investing valuable time, energy and household financial resources into one individual (also see Merten *et al.*, 2010). This meant that families had to redirect some portions of their incomes to secure the health and care of PLHIV. In other households, where people reported there were inadequate resources, people had to prioritise certain expenses over others depending on what they deem mostly important. When other household needs were considered important than ART related expenses, PLHIV suffered consequences of being interrupted from treatment.

As noted above, I intended to assess how managing incomes could potentially impact on the adherence behaviour of PLHIV. I found that PLHIV could move from being reluctant to being adherent on treatment, and at times, they interrupted treatment due to life changes often brought on by economic conditions. I found that there were various determinants surrounding ART adherence that operated beyond the influences located at the household level. The impact of income management on ART adherence is navigated at, but not limited to, the micro-level. There are structural aspects including political, social, and economical factors that cannot be left unaccounted for when assessing ART adherence behaviour of PLHIV. I propose that solutions around interrupted ART and non-adherence should not only be made household-specific based. Implementation frameworks should endeavour to combine structural aspects, behavioural interventions, and the future of HIV responses should embrace different approaches for different populations (also see Shanaube & Bock, 2015). We need to amend the health services at the level of microsystem, mesosystem, exosystem, macrosystem, and chronosystem in order to improve optimal adherence of PLHIV in economically constrained settings.

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Appendix A: Excerpt from discussion guide – Module 2

Discussion guide
(Active families in quali-cohort – Module 2)

Purpose: *The HPTN 071 (PopART) qualitative cohort enables us to contextualise the experiences of people living with HIV (PLHIV) or people living in the context of HIV in relation to scaled-up ART access regardless of CD4 count. In South Africa, this transition means moving from approximately three million PLHIV on ART to approximately six million PLHIV eligible for ART. Scaling up ART uptake will require significant shifts in both how HIV-related services are delivered (in health facilities and in community spaces) and client testing, treatment initiation, and adherence patterns. These patterns are interrelated with intrapersonal, interpersonal and social contexts, which shape, for example, individual life course trajectories, patterns of disclosure, and gendered power dynamics. Module 2 builds on initial interactions with families in the qualitative cohort. In it, we aim to continue to build relationships with families and to understand how families 'get by'. This includes exploring family income sources and expenditure, as well as trying to understand how the availability (or lack of) income influences people's ability and willingness to engage with the health care system. In understanding family spending, we will also be able to gauge where health and health care fit into daily family expenses. In households or families affected by HIV, understanding how families negotiate income, expenses and living costs also provides the lens through which we can view what the direct and indirect costs associated with HIV, ART and care is. We are also able to gauge where ART and treatment fit into household priorities and understand what potential barriers to treatment entail. The goal of the discussion guide is to help facilitate discussion about key topic areas. It includes four discrete activities to be completed with families in the cohort. The guide should be used flexibly with each family over the course of several interactions with them. It is to be used alongside the ARF (Activity report form) and RIDD (Reflection on interviews/discussion document).*

Objectives:

- *To continue building your relationship with the family members.*
- *To ensure that family members understand and engage with our interest in the economics of life and health.*
- *To understand family income and survival strategies*
- *To understand family spending and decision making about spending.*
- *To explore to what extent 'health' (including medical care, health care, healthy living, caring for others) forms part of expenses.*

Form of data recording: *(1) Audio-recording of* ***all talk*** *from "Preamble" to "Closing". (2) Notes of key points per topic area handwritten by the facilitator into the ARF. (3) Still photographs of relevant images.*

Expected time needed per use: *2-3 days (total)*

Potential additional themes that might be explored:

- Financial decision making- who makes decisions about the finances
- Informal economy/Illicit activities
- Social support, childcare, chores, favours, gifts
- Nutrition and food choices

Activity/Topic area 1 – Pie chart for family income

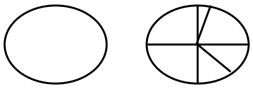
Have blank cards and a marker ready to list items for pie chart. Have a roll of toilet paper ready to use as outline for your pie charts. Use the income pie chart to engage the participants with how to use a pie chart to represent proportions. Guide participants where necessary. Create a circle/outline with the toilet paper. Use other pieces of toilet paper to create sections, as described by the participants. Encourage participants to move the lines to be more and more accurate. Further, encourage different participants to have a chance at moving the lines. What you are trying to elicit is discussion between participants.

We understand that people have different ways of making a living and getting by. In our families, we also have different ways of sharing income and expenses.

- Can you tell us a little bit about who contributes to the income for this family/house?
- Can we now list (on these cards) all the different places where, in a typical day/week/month (*depending on participant*), the income in your house comes from?
- One way of showing which sources of income are bigger/smaller than other sources is by pretending that all the income is a pie/cake. We want to understand what the different ‘slices’ (income sources) are that form part of the pie/cake. Remember, some slices are bigger/more important than other slices. We will use this round piece of toilet paper to make the pie/cake. Please help us to identify how big each of the ‘slices’ are that we just listed.
- We understand that family income is sometimes about more than just money. What else do you receive that helps you get by?

Activity/Topic area 2– Pie-charts for family expenses

Have blank cards and a marker ready to list items for pie chart. Have a roll of toilet paper ready to use as outline for your pie charts. For this activity, ask the participants to complete the chart with little intervention from the researcher. Encourage different participants to have a chance at moving the lines. What you are trying to elicit is discussion between participants.



- First, perhaps we can list all of the things that cost money or how money is spent.
- We know that people often also need to send money to family members that are not part of their household. Do you have any family like this?
- Who decides where/how money is spent?
- Let’s look at the pie/cake and talk about how money is spent. Remember, different expenses are bigger/smaller than other sources. We want to understand what the different ‘slices’ (expenses) are that form part of the pie/cake. Remember, some slices are bigger/more important than other slices. We can again use this round piece of toilet paper to make the pie/cake. Please help us to identify how big each of the ‘slices’ are that we just listed.
- As we have discussed, we know that money is at times not available. What do you do when you want/have to do (X) but you don’t have any money?
- We know that when someone is sick, there are often some expenses. Can you please tell me about the last time when you / member of your family/ child was sick.
- Can you tell me if there has been an instance where health or illness has made it difficult for you /your family to get by?

Appendix B: Excerpt from discussion guide – Module 4

Qualitative Cohort
Discussion Guide - Module 4

Purpose: *The HPTN 071 (PopART) qualitative cohort enables us to contextualise the experiences of people living with HIV (PLHIV) or people living in the context of HIV in relation to scaled-up ART access regardless of CD4 count. In South Africa, this transition means moving from approximately three million PLHIV on ART to approximately six million PLHIV eligible for ART. Scaling up ART uptake will require significant shifts in both how HIV-related services are delivered (in health facilities and in community spaces) and client testing, treatment initiation, and adherence patterns. These patterns are interrelated with intrapersonal, interpersonal and social contexts, which shape, for example, individual life course trajectories, patterns of disclosure, and gendered power dynamics. As we begin to prepare for closing with our cohort, we want to be sure that we have covered essential topics related to the HIV care continuum and patterns of uptake with all our families. As such, in Module 4 we will talk about each step along the HIV care continuum, i.e., testing, linking to care, and remaining on ART. We will do this to explain patterns of uptake for various types of individuals, families, and communities. We aim to describe motivators and challenges to uptake at each step of the HIV care continuum, as well as the social processes that may include or exclude certain types of individuals. The lessons that we learn will help inform the national scale up of the HIV programme to offer universal access to ART.*

The goal of the discussion guide is to help facilitate discussion about key topic areas. It includes 5 discrete activities to be completed with families in the cohort. The guide should be used flexibly with each family over the course of one or two interactions with them. It is to be used alongside the ARF (Activity report form) and RIDD (Reflection on Interviews/Discussion Document).

Objectives:

- *To begin to prepare for the closure of the qualitative cohort*
- *To assess understandings of HIV, HIV testing, and treatment*
- *To explore community members' perceptions and experiences of the PopART intervention (the household and clinic interventions)*
- *To explore the unique experiences of people living with HIV as they navigate the HIV care continuum*

Form of data recording: *(1) Audio-recording of* ***all talk*** *from "Preamble" to "Closing". (2) Notes of key points per topic area handwritten by the facilitator into the ARF. (2) Still photographs of relevant images.*

Expected time needed per use: *3-4 hours*

Topic area 1 – Popular understandings of HIV in the community

First, we would like to talk about general understandings of HIV in your community.

- When people talk about HIV, they do not always use the word HIV or AIDS.
- What other words come to mind if someone talks about/you think about HIV?
- How does HIV affect your community? Has this changed over time?
- What are some of the health concerns that worry you most?
- For you, how do you see HIV compared to other illnesses?
- Tell me what you have heard or know about each of the following:
    - Prevention of mother-to-child transmission (PMTCT)
    - Pre-exposure prophylaxis (PreP) / post-exposure prophylaxis (PEP)
    - Treatment as prevention (TasP) or universal test and treat (UTT)
- We've been working in this community over the last couple years and some of the things that we think have changed over time is the way that people think about HIV, and the way people think about sex after being diagnosed with HIV. What do you think?

People living with HIV – Extended DG for individual interviews

- (TIMELINE) Researcher to draw *PLHIV's timeline of testing and treatment.*
- (DISCLOSURE) Have you shared your status with anyone?
  (Researcher uses disclosure network. Mark the people who knows their status, why they disclosed to each of the people and when (the date))
- (MANAGING HIV) What are some of the challenges of staying healthy – including using ART and other ways of managing HIV?
  It is a fact that many people find it challenging to go onto any kind of lifelong treatment. Tell me about some of the challenges you have experienced with taking ARVs every day.
- (LINKING TO CARE/STARTING ART) Please tell me about the first time that you went to the clinic after testing positive.
- (INITIATION) Tell me about when you started on ART
- (ART INTERRUPTIONS) Since you started using ART was there a time when you stopped taking it, even if just for a short while?

Appendix C: Excerpt from transcription guide

1. General Instructions

When transcribing interviews, all recordings should be typed verbatim. This means that everything should be typed word for word, exactly as it was said, including grammatically incorrect sentences, incomplete sentences and words and nonverbal or background sounds (e.g. laughter, sighs, coughs, claps and other sounds). Transcription should be done according to the symbols provided in this document. All transcriptions should be clearly labelled. The identities of researchers and participants should remain anonymous and codes will be used in transcriptions to identify participants. **The template MUST be used.** The template can be found on hard drive 2 and please save the template to your computer.

1.1 General Formatting

The following formatting is to be used when transcribing all key informant interviews (KII) and group discussion (GD) interviews, the template already has this formatting set up:

1. Arial 10-point

2. Margins: Normal

3. All text to begin indented

4. Entire document to be left justified

5. Lines to be numbered

6. Watermark: "Confidential"

1.2 Content

Interviews should be transcribed **verbatim** (i.e., typed word for word, exactly as said), including any nonverbal or background sounds (e.g., laughter, sighs, coughs, claps, snaps fingers, pen clicking, and car horn).

- Nonverbal sounds to be typed as indicated below
- Other **nonverbal sounds** shall be typed in **double brackets**, for example ((police siren in background))
- If interviewers or interviewees mispronounce words, these words should be transcribed as the individual said them. **The transcript is not to be "cleaned up"** by removing foul language, slang, grammatical errors, correcting misuse of words or concepts, or explaining what the participants "meant to" say; only what was *actually* said.
- All **numbers** (except when using transcriber codes and site numbers) must be written out in word format (i.e. 12 will be twelve).
- All currency to be written out (i.e. R12 will be twelve rand; $13 will be thirteen dollars).
- Time must also be written out in words and indicated in double brackets (i.e. twelve o'clock **((12:00))**).
- No sentence should be started with capital letters. Only use capital letters for identifiers (i.e. names of: people, place, gods, institutions, medications, months and days).

2. Transcription Symbols

Transcription[11]	**Symbols**	**Short Description**
Phrase		
Word	SPACE	Space between words
Pause		
pause, timed	(1.2)	Silences and pauses timed
pause, short	..	Silence too short to time
pause, long (untimed)	…	Longer silence unable to time
latching	=	Speaker is interrupted
Participation		
participant/turn attribution	S20_03	Participant identification
researcher/interviewer		
unidentified speaker	#;	
uncertain speaker	#S20_03	
Other Identifiers	+word+	
Sequence		
overlap (single)	[ ]	
overlap (2nd)	[$_2$]	
Disfluency		
truncated/cut-off word	wor-	
Vocalism		
breathe (in)	(H)	
exhale	(Hx)	
vocalism	(SNIFF)	
click	(TSK)	
laugh pulse	@	
laughing word	wo@rd	
glottal stop, creak	(%)	
glottalized word	w%ord	
Manner and Quality		
manner/long feature	<words>	
Manner/short feature	>words<	
piano, attenuated speech	°words°	ALT+0176 for °
forte	^words^	
smile quality	<☺word>	:) for ☺
Inaudible		
unintelligible	###	
uncertain	#word	
comment/notes	((words))	
Boundary/Closure		
terminative	.	
continuative	,	
appeal (final)	?.	
appeal (continuing)	?,	

2.1 Recording Phrases and Pauses

Phrases	
word	SPACE
Pause	
pause, timed	(1.2)
pause, short	..
pause, long (untimed)	…

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[11] Du Bois: Comparison of Transcription Symbols.
Available: http://www.linguistics.ucsb.edu/projects/transcription/A04comparison.pdf

latching	=

All phrases should be separated by a single space.
All pauses should be noted. If a participant pauses for a number of seconds, the time period that the pause lasts should be indicated in brackets.
New phrase start with a small letter

Example:

27	**R23**	you're about to get a new task, (2.5) I think.
28	**S20_03**	I am (1.0) not worried.

If there is a micro-pause (a pause that can be heard but that is too short to measure), the time lapse is indicated with the two ellipses. If the pause is longer, but untimed, the transcriber should make use of three ellipses.

Example:

33	**R23**	you're about to get a new task.. I think.
34	**S20_03**	I am not worried…

Equals' signs mark the immediate 'latching' of successive talk with no interval or pause in between. There should not be a full stop or comma after the latching symbol.

Example:[12]

11	**R23**	you're about to get well you're not about
12		to get married but you (0.2) are getting
13		married in the near future=
14	**S20_03**	=yes.

2.3 Identifying Participants

Participation	
speaker/turn attribution	S20_03
unidentifiable speaker	S20_M2 / S20_W1
uncertain speaker	#S20_03

Each respondent is to have a unique ID. Respondents will be identified through connecting the site ID adjacent to a respondent number. (Please see discussion in *Section 5* above).

Example:

"S13_01" will be the first respondent in site "S13" while "S18_02" will be the second respondent in a different site.

If a participant participates in two or more aspects of the same study they will be given multiple unique codes relevant to each aspect of their participation. In group discussions speakers should be coded with the site code, a "W" or "M" (woman or man) as well as a number. If the speaker's sex is unclear indicate this with a # sign. If other organisations, companies or people are identified by the participants in discussion, this should be indicated with plus sign on both sides of the name.

Example"

34	**R23**	what do you think S20_W1?.
35	**S20_W01**	I am not sure
36	**S20_#04**	I think it is true that +Desmond Tutu TB Centre+ is like that.

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[12] Example found and modified from: http://extra.shu.ac.uk/daol/articles/v1/n1/a1/transcript.pdf

Appendix D: Informed consent form

INFORMED CONSENT FORM – SOCIAL SCIENCE PARTICIPANTS

PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT FORM

Title of Research Study:	**Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART): A cluster-randomized trial of the impact of a combination prevention package on population-level HIV incidence in Zambia and South Africa**
Protocol #:	HPTN 071, Version 1.0, 26 October 2012 DAIDS ID: 11865
Sponsor:	National Institute of Allergy and Infectious Diseases National Institute of Mental Health (U.S. National Institutes of Health) Office of the United States Global AIDS Coordinator Bill and Melinda Gates Foundation
Investigator of Record:	**Professor Nulda Beyers**

Research Site Address (es):

Site: Delft South Clinic **Address: Cr Main Rd & Boyce St**	**Site: Bloekombos Clinic** **Address: Sam Nokasela Avenue**	**Site: Ikwhezi clinic** **Address: Simon Street Nomzame**
Site: Town 2 Clinic (outreach) **Address: c/o Zibonele and Manyano Street**	**Site: Kuyasa Clinic** **Address: Ntlazana Street, Khayelitsha**	**Site: Luvuyo Clinic** **Address: Hlela Road, Makaza**
Site: Dalevale Clinic (outreach) **Address: Symphony Avenue,**	**Site: Cloetesville Clinic** **Address: Tennant Street**	**Site: Wellington Clinic (outreach)** **Address: Wellington Municipality**

Daytime telephone number(s): **021 983 9114**

24-hour contact number(s): **083 572 1470**

Introduction to the forms
Please ask the researcher staff to explain any words or procedures that you do not understand clearly, both in this information form, and throughout your interaction with them.

The purpose of this form is to give you information about the research study you are being asked to join. By signing this form, you are giving permission to the researchers to use the information you share with them as research data. The form describes the purpose, procedures, benefits, and risks of the research study so that you can know why the researchers are doing this research, why you are being invited to participate, and what this participation will mean. You should take part in the study only if you want to do so. You may choose not to join the research project or withdraw from this study at any time. Choosing not to take part in this research will not in any way affect the health care or benefits that you or your family will receive. Please read this Informed Consent Form for Social Science Participants and ask as many questions as needed. You should not sign this form if you have any questions that the researchers have not been able to answer in a way that you understand.

This study is being funded by the U.S. National Institutes of Health, the Office of the United States Global AIDS Coordinator, and the Bill and Melinda Gates Foundation.
There are several key points that you should be aware of before signing the consent form. These key points have been separated into sections under **bold headings** below; the first of these sections about your participation being *voluntary*.

Your participation is voluntary
You *do not have to* be part of this study. This means that being part of the study is your free choice, not because you feel pressure to participate. If you decide not to participate now, you are welcome to inform the researcher of this immediately. You are also welcome to not participate in particular parts of the study as we go, either by keeping silent, or indicating to the researcher to skip that section as you go. After completing the data collection with you, you also have the opportunity to tell the researcher that you would like to withdraw your participation from the study and your contribution will be excluded from scientific analysis. If you do decide not to participate, to skip some sections, or to withdraw your data contribution this will *not* influence the care you are entitled to at health facilities. Your choice to participate or not is your choice, and we respect that. From our side, we also make the commitment to protect the information about your choice to participate or not safe (see section on "**participant confidentiality and privacy**" below).

Purpose of the Research (what is this about?)
The research you are being asked to participate in is one part of a larger study. The larger study is called HPTN 071 (PopART). It is evaluating whether a program to try to reduce HIV infection in a community like yours works or not. This HPTN 071 (PopART) study is being done in 21 communities in total, including 9 communities in South Africa (all in the Western Cape), and 12 other communities in Zambia. It is estimated that about 600,000 adults are included in this research. If you would like more information about the HPTN 071 (PopART) evaluation, please ask the researcher who can also supply you with a study fact sheet.

Part of this bigger study called HPTN 071 (PopART) is what we as the researchers call the social science component. This social science component is the part of the study that helps us to understand the experiences of people implementing the research, living in the study communities, or who are important in other ways. The social science component aims to give detailed, real, contextual explanations of how and why things happen as they do to complement the larger evaluation of 'if' the intervention works or not. Typically, most of this social science component involves spending time with people, observing their daily lives, and listening to their stories. Broadly, there are three aims to the social science components of HPTN 071 (PopART); (1) telling the story of the study and the intervention it is evaluating, (2) explaining peoples' choices to take-up offers of HIV counseling and testing and ante-retroviral therapy or not, and (3) describing the social context of life in the study communities (for example, how and why things like unemployment is important to the story of health). More information on why the social science research team would like you to participate is included in the section on "**participant eligibility – why am I being asked to participate**" below.

Participant eligibility – why am I being asked to participate

As part of the social science components of HPTN 071 (PopART), it is of utmost importance that the everyday lives of community members in the study communities are described; especially in relation to the way health issues (including HIV) intersect with wider social issues and contextual experiences. You are being invited to participate because you live in one of these study communities. We believe that you have valuable information to share about your life and the lives of people living in your community and we would be very grateful if you share this with us.

What will happen during this study?

The social science field team would like to spend time with you as representatives of people living in the HPTN 071 (PopART) study communities. In order to properly understand your lives (it is our assumption that everyone lives complex, complicated, and interesting lives) we would like to spend a significant portion of time with you; at your homes, in the places you go to during the day and evening, and anywhere else you think that would help us to clearly understand your life. For most participants, we will spend at least a week worth of interactions with them at the beginning (not quite living with them, but definitely visiting for a while), then call again to see how things are about a month later, and at least one in-person follow-up visit about 6 months later. During this time, the research team will ask you questions and may ask you to do some activities (like ranking of alternatives). The research team will make notes of what they see and hear and will also keep records like audio recordings and photographs of relevant parts of their observations. You are being invited to participate in all of these interactions. The research team would also like you to refer us to other people that are your significant others, or otherwise important to understanding your life that we can have discussions with during the time spent with you.

What are the possible risks or discomforts?

There is a risk that some of the questions we ask may be uncomfortable and may make you feel worried or embarrassed. If any of the questions make you feel upset, the interviewer may go to another question or stop the discussion. The researchers may ask questions or ask for more detail in your answers than would be normal if you are having a discussion with friends or in another social context. The researchers are not doing this because they are nosy or trying to judge you. Rather, it is done to remain true to your real experiences and opinions. If you feel the need for follow-up counseling services, please indicate this to the research staff, and you will be referred to appropriate services. Thank you in advance for your honesty and candor as the real value to this research is telling such stories truthfully.

There is also a risk that being seen with us might lead other people to make assumptions about you. As part of the HPTN 071 (PopART) study, we have tried to make it common knowledge about why we are in the community (to learn about HIV prevention). However, some few people might still make wrong assumptions. Please inform us if you ever feel that this is the case and we can make alternate arrangements, for example finding a private or neutral venue to meet.

What are the potential benefits?

This is a research study, not a service delivery programme. You will not receive any direct benefit from being part of this study, other than the opportunity to share your experiences with us. The aim of the research is to produce information that will benefit people living in this place, in Africa, and across the world.

Are there any alternatives to participation?

The research study is an opportunity for us to learn from you, not the other way round. If you decide not to participate in this study, but would like to receive more information about public health concerns like HIV, or you would like to access HIV tests and other services, please visit your local health facility.

Participant confidentiality and privacy

Confidentiality means we as the research team will protect your identity and take steps to make sure that your story, the opinions that you express, and other identifying images or recordings are separated from your identity as a person. We do this so that someone else cannot read one of our reports or see our presentations and know 'ah, it was *you* who said that'. We keep this confidentiality in everything that we do and in a number of ways. For example, when we save the data or recordings we do not save it with your name, we save it with a unique study number. And, if in a story that you tell us, you use your own name, we change your name to a fake name when we report on that story. And, if we see you again after this, we will not mention that we had already interacted with you as a research participant, we will pretend that we had not met you. We also store all the data in a safe and secure way, so only study staff can have access to it. All your personal information (name, address, phone number) will be protected by the research staff. This information will not be used in any publication of information about this study.

To protect your privacy, when you wish it, the researcher will meet with you in a private area where others cannot overhear conversations with you.

There are some people who may review the records of your data. They do this to check that we the researchers are treating you in the correct way and otherwise adhering to guidelines for good scientific practice. The people who may review your records include: Stellenbosch University Health Research Ethics Committee, local regulatory agencies, US National Institutes of Health (NIH), study staff, and study monitors. Institutional Review Boards (IRBs) or Ethics Committees (ECs) are committees that watch over the safety and rights of research participants.

There are some things that if you told us them we would be legally obliged to report this to the relevant authorities. For example, if we observe child abuse, we would need to report this to the Ethics Committee immediately and this matter will be referred to appropriate services.

Long term storage of the data and inclusion in a social science databank

If you sign the consent document, you are agreeing to allow the researchers to use the information you share with them to answer the questions described above. Hard copies of the data will be stored in secure, lockable cabinets and soft copies on secure, password-protected computer platforms. The data will be stored for a minimum of 7 years and destroyed after 7 years or after study completion.

You are *also* agreeing to allow researchers to store your data for analysis in other ways and to answer other relevant research questions. All data stored in this way will be treated as confidential as described in the section above on "**participant confidentiality and privacy**". We ask to store the data and use the data in this way for four reasons:

(a) To reduce the burden on research communities because multiple researchers do not have to 'keep coming back' asking very similar questions
(b) Enable researchers to understand patterns over much longer time scale than is usually possible because we will have contributions like this from multiple research studies
(c) Offer opportunities to students to analyse real data that it would usually be too logistically challenging for them to collect and thus improve social science training
(d) Help ensure that all such social science research is conducted with the same rigor and at the same high standard

Every new study or analysis that wants to use the data you contribute will still need to receive approval to do this from an appropriate ethics review committee, and there are strict controls in place as to who may access such stored data and for what purpose.

If you ***DO NOT*** want your data to be included in this databank, please indicate this to the research staff now and they will show you how to indicate this on the consent form when you sign consent. Otherwise, it will be assumed that you are happy for the data to be included as described.

What happens if I am injured by participating in this study?

It is very unlikely that you could be injured as a result of participating in this study. Nothing that we will be asking of you should place you at risk for injury (we are just talking with you and spending time with you). However, if you are injured while participating in this study, immediate treatment is more important than the research study. To be clear though, this care will be the normal care available from the local Department of Health facilities. Participation in this study does not give you access to any extra care or support. There is no program for compensation either through this institution (University of Stellenbosch) or the United States NIH. At the same time, you will not be giving up any of your legal rights to care by signing this Informed Consent Form for Social Science Participants.

What are some reasons why the researchers may decide to withdraw your participation in the study?

You may be withdrawn from the study without your consent for the following reasons:

- The research study, or this part of the study, is stopped or cancelled
- The study staff feels that completing the study or this part of the study would be harmful to you or others
- The scientific goals for the research have already been met and continuing would be of no further scientific benefit
- If you as participant would not be able to, or would be unwilling to participate in the study in such a way that is in accordance with the needed study procedures

Persons to Contact for Problems or Questions

If you have any questions about your participation in this research study, your rights as a research participant, or if you feel that you have experienced a research-related injury, contact:

1. Dr Peter Bock, Co-Principal Investigator, Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, University of Stellenbosch. Telephone: 021 9389062. Email: peterb@sun.ac.za

2. Principal Investigator: Nulda Beyers, Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, University of Stellenbosch. Telephone: 021 938 9114. Email:nb@sun.ac.za

If you have any questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

1. Independent Review Board/Ethics Committee: Mr Franklin Weber, HREC coordinator, Health Research Committee 1, Stellenbosch University Health Research Ethics Committee, Tygerberg Campus. Telephone: 021 938 9657.

PARTICIPANT'S STATEMENT OF CONSENT_Activities 28, 30, & 31

HPTN 071 (PopART) – Social Science Component

- I have been given sufficient time to consider whether to take part in this study.
- My taking part in this research study is voluntary. I may decide not to take part or to withdraw from the research study at any time without penalty or loss of benefits or treatment to which I am entitled.
- The research study may be stopped at any time without my consent.
- I have had an opportunity to ask the researcher questions about this research study. My questions so far have been answered to my satisfaction.
- I have been told what participation would mean in terms of what may be asked of me and how long this may take; including that the research may take pictures and make audio and recordings.
- I have been informed of the procedures that may be performed during the research study.
- I have been told what the possible risks and benefits are from taking part in this research study. I may not benefit if I take part in this research study.
- I do not give up my legal rights by signing this form.
- I have been told that before any study related procedures are performed, I will be asked to voluntarily sign this Informed Consent Form for Social Science Participants.
- I have been told that unless I indicate otherwise below, the data I contribute to this study will be stored in a databank for future social scientific analysis and research.
- I will receive a signed and dated copy of this Informed Consent Form for Social Science Participants.

If you have either read or have heard the information in this Informed Consent Form for Social Science Participants, if all of your questions have been answered, and if you agree to take part in the study, please print and sign and your name and write the date on the line below.

I voluntarily agree to take part in this research study.

______________________________	______________________________
Participant's Name and Surname (print)	Participant's Signature

____
Date

I, the participant, indicate my preference that the data I contribute be *EXCLUDED* from the social science databank (that is, the data I contribute will only be used for the HPTN 071 (PopART) study and *NOT* other research) by signing again here: (otherwise leave blank)

____

I certify that the information provided was given in a language that was understandable to the participant.

______________________________	______________________________
Study Staff Name and Surname (print)	Study Staff Signature

____
Date

(*as appropriate*) I certify on behalf of the participant that they take part in this study voluntarily.

______________________________	______________________________
Witness' Name and Surname (print)	Witness' Signature

____
Date

We work at the Desmond Tutu TB Centre, Paediatric Department, Stellenbosch University and part of our work is to do research, train students, raise awareness and give talks and presentations on TB, HIV and other health concerns in communities. The photos and recordings we make are part of the research process, which we can analyse to better understand health issues from the perspective of community members. We also give presentations to fundraise for research and want to put up work related pictures in our offices. Photographs and quotations are also very useful to illustrate our reports as it helps to explain our findings to funders and others.

It is our practice when using photos or making recordings during research and training, to obtain your signed permission before including photos or anonymous quotations of you/your business/ your organization/ your home or child. No names or surnames will be used. The photos will not be used for media publications.

Hereby I _____________________________________ give permission that the photo/s taken/recordings made today in which I/ my business/ my organization/ my home/ my child appear, may be used for the following purposes:

- ○ Providing contextual detail to qualitative research
- ○ Training of and raising awareness under students
- ○ Talks and presentations by staff from the Desmond Tutu TB Centre and other researchers
- ○ To put up in the Desmond Tutu TB Centre
- ○ Presentations to fundraise for TB research from corporate businesses
- ○ To illustrate reports written by the Desmond Tutu TB Centre
- ○ To be included as part of a social science database on ‘health in context’ in southern Africa

Signed at ____ (city/suburb/community)

on ____________________________(date).

____________________________	____________________________
Signature of representative	Signature of recorder
____________________________	____________________________
Name and surname of representative	Name and surname of recorder

Appendix E: HREC - Ethics approval letter

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New Application

20/01/2020

Project ID :11776

HREC Reference No: S19/10/227

Project Title: Exploring the management of household income and effect on ART adherence.

Dear Mr Abenathi Mcinziba

We refer to your response to stipulations received on 08/01/2020. Please be advised that your submission was reviewed by members of **Health Research Ethics Committee** via **expedited** review procedures on 20/01/2020.

Please note the following information about your approved research protocol:

Protocol Approval Date: 12 December 2019

Protocol Expiry Date: 11 December 2020

Please remember to use your Project ID 11776 and Ethics Reference Number S19/10/227 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process. **After Ethical Review**

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary health care facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/11776

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Melody Shana

Coordinator

HREC

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Page 1 of 2

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review
Board (IRB) Number: IRB0005240 (HREC1)·IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects;the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes andStructures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix F: Letter for use of data permission

16 September 2019

Dr Barsdorf
Health Research Ethics Committee
Division for Research Development
Stellenbosch University
Cape Town

Dear Dr Barsdorf

Re: Mr Abenathi Mcinziba's application for secondary analysis of HPTN 071 (PopART) [N12/11/074] data to be included in his MPhil in Transdisciplinary Health and Development Studies dissertation.

Many thanks for considering this letter. This proposed research for an MPhil degree; "*Exploring ways in which the management of household incomes affect antiretroviral therapy (ART) adherence of people living with HIV in the Western Cape*" has been discussed with the HPTN 071 (PopART) leadership team, including the protocol chair (Prof Hayes) and co-chair (Prof Fidler), who are supportive of the planned research.

We trust that you find this in order and are happy to answer any queries by HREC either via email or in person.

Sincerely

On behalf of the HPTN 071 (PopART) leadership

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jou kennisvennoot • your knowledge partner

Desmond Tutu TB Sentrum ⌖ Centre ⌖ Iziko

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Direkteur ⌖ Director: Prof Anneke Hesseling (annekeh@sun.ac.za)