

Sarah Mariam

Barriers to Treatment Adherence among ALHIV and Strategies to mitigate them: A viewpoint of Healthcare providers in Zimbabwe

Master's thesis in Global Health

Supervisor: Prof. Jon Øyvind Odland & Dr. Grace McHugh

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Faculty of Medicine and Health Sciences

Department of Public Health and Nursing



Kunnskap for en bedre verden

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Dedication

I dedicate this research to my mentor; my fiancé, Mr. Daud Nayer, PhD Research Fellow at the University of Strathclyde, Glasgow, who has always stood like a rock beside me, uplifting and enlightening me throughout every step of this endeavor. I fall short of words to thank you, but to put it briefly, without your unflinching and sincerest help, support and trust, it would not have been envisioned or even achievable. Thank you Daud, for always sparing out the time to assist and guide me in every humanly possible way, regardless of the enormity of your own academic and personal engagements. Your incessant presence yet in this project too, has made it a worthy venture.

Abstract

Introduction

Although Anti-retroviral Therapy (ART) has succeeded in lowering mortality rates among all age groups in Zimbabwe, despondently, mortality rates among adolescents living with HIV (ALHIV) have remained the same. With a well-documented poor adherence to ART, ALHIV have higher mortality rates, making non-adherence to ART among ALHIV a global public health problem. This paradoxical increase in mortality among ALHIV demands research into the exploration of obstacles faced by adolescents living with HIV in Zimbabwe in adhering to ART. This study aims at assessing barriers to treatment adherence among ALHIV living in Zimbabwe, in order to propose effective and efficient strategies for improving ART adherence among them.

Methodology

To comprehend the antecedents behind this phenomenon, a descriptive qualitative study, consisting of 18 face-to-face, semi-structured, in-depth interviews were employed. Data was collected through purposeful sampling from healthcare providers (9 counsellors, 6 nurses and 3 medical doctors) working under the BREATHE trial of Biomedical Research and Training Institute (BRTI) and from three health facilities; Harare Central Hospital, Parirenyatwa Hospital and Rutsanana Poly Clinic, in Harare, Zimbabwe. Following the interpretive paradigm, an inductive approach was used to analyze data through Thematic analysis, which resulted in formation of four themes.

Results

The four themes discovered, depicted the barriers to treatment adherence among ALHIV, i.e. Social, Healthcare system, Medication and Individual barriers. Data analysis and interpretation of results showed that, simultaneous to the formation of treatment non-adherence by these barriers individually, there also lies an inter and intra-relationship among the barriers, where one barrier instigates the formation of other barriers. Among the barriers revealed, Social barrier was found to be the most diverse and overarching barrier that instigates all other barriers.

Conclusion

The recognition of treatment adherence barriers identified through this research, resulted in formation of effective strategies, intended for all stakeholders involved in the treatment of ALHIV. The inter and intra-relationship model found through this research, underscores that

the social barriers emerge as the most pronounced obstacles in treatment adherence of ALHIV at numerous levels. Therefore, social barriers must be culminated, in order to prevent the aggravation of other barriers. The proposed strategies, hence, also serve to direct the formation of prospects for future research to improve ALHIV's adherence to ART.

Keywords: HIV, ALHIV, Anti-retroviral Therapy, Treatment Non-adherence.

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Abbreviations and Acronyms

SSA	<i>Sub-Saharan Africa</i>
HIV	<i>Human Immunodeficiency Virus</i>
ALHIV	<i>Adolescents Living with HIV</i>
AIDS	<i>Acquired Immunodeficiency Syndrome</i>
ART	<i>Anti-retroviral Therapy</i>
PLWHIV	<i>People Living With HIV</i>
ARV	<i>Anti-retro Viral</i>
FDA	<i>Food and Drug Administration</i>
UNAIDS	<i>Joint United Nations Programme on HIV and AIDS</i>
WHO	<i>World Health Organization</i>
IAS	<i>International AIDS Society</i>
SDG	<i>Sustainable Development Goals</i>
CDC	<i>Centres for Disease Control and Prevention</i>
BRTI	<i>Biomedical Research & Training Institute</i>
PIS	<i>Participant Information Sheet</i>
TA	<i>Thematic Analysis</i>
REK	<i>Regional Committee for Medical Research Ethics (REK), Norway</i>
USD	<i>United States Dollar</i>
ODD	<i>Once Daily Dosing</i>
FDC	<i>Fixed-Dose Combination</i>
ADR	<i>Adverse Drug Reaction</i>

Operational Definitions

Adolescents: Refers to the individuals between 10 and 19 years of age (1).

ALHIV: Adolescents living with Human Immunodeficiency Virus (ALHIV), include both perinatally and sexually infected individuals (2).

Anti-retroviral Therapy (ART): The daily use of a combination of HIV medicines for treating HIV (3).

Treatment adherence: The extent to which a person adheres to the treatment recommendations from a healthcare provider (4).

Non-adherence: The inability to follow treatment plans, like taking medications at the prescribed time and frequency (4).

Healthcare providers: Healthcare professionals/staff i.e. HIV Counsellors, Nurses and Medical doctors, experienced and involved in the treatment and care of adolescents living with HIV.

Treatment Adherence Barriers: The hurdles encountered in adhering to ART treatment are called treatment adherence barriers. The World Health Organization (WHO) categorizes some of the barriers as those related to: healthcare team, condition-related factors, social and economic factors, system-related factors, therapy-related factors, and patient-related factors (5).

Effective strategies: The strategies designed for and aimed at successfully improving treatment adherence among ALHIV.

Chapter 1: Introduction

This chapter serves to give an introduction to the problem of treatment non-adherence among adolescents living with HIV (adolescents, aged 10-19 years; World Health Organization ;WHO (1)), in the background of the global epidemic of HIV. In addition, it highlights the severity of the disease in Sub-Saharan Africa (SSA), as well as in Zimbabwe (the study site of this research), along with an overview to the treatment of HIV. Therefore, setting the stage to underscore the urgency of the problem of treatment non-adherence among adolescents living with HIV (ALHIV) in Zimbabwe. Furthermore, this chapter also delineates the research problem, research questions, aims, objectives and significance of the study, so as to establish an understanding for the execution of the entire research.

1.1 Background

1.1.1 HIV a global challenge

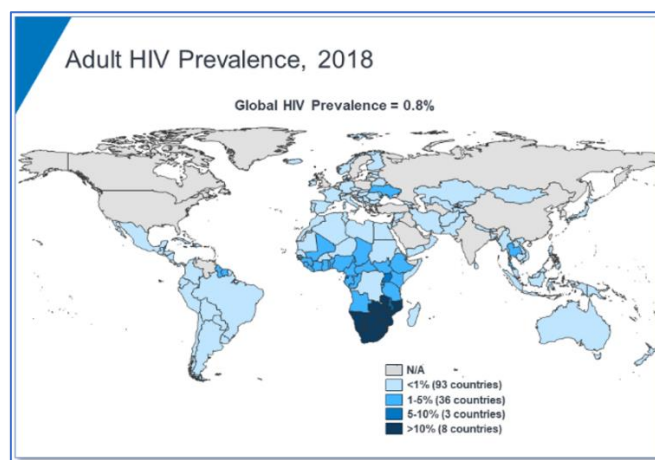
Even three decades after the cognizance of the Human Immunodeficiency virus (HIV), declared to be the causative agent of Acquired Immunodeficiency Syndrome (AIDS), HIV continues to be a global public health concern and a pandemic (6) (7). The fatal virus attacks the human body by impairing the immune system through destruction of the CD4 cells (a type of immune cells that synchronise immune response via stimulation of other immune cells i.e. macrophages, B cells and CD8 cells, to fight off infections) (3) (6). AIDS is the terminal stage of HIV, wherein the body is critically damaged and immune compromised, as a result, the infected person is prone to numerous infections/comorbidities (hence called a syndrome), and survival without medications at this stage is one year at maximum (8). In defiance of the efforts made to curtail the disease, even till the year 2018, a striking 1.7 million people were newly infected with HIV and 770,000 people were reported to have succumbed to AIDS-related illnesses alone (9) (10). Exhaustively, since the emergence of the epidemic in 1985 till now, 74.9 million people have been infected with HIV globally, while those that have died due to AIDS-related illnesses approximate to 32 million (11). Surprisingly, a staggering portion of the people infected due to HIV/AIDS reside in Sub-Saharan Africa (SSA) (12).

1.1.2 HIV in Zimbabwe

The global distribution of HIV clearly illustrates that the African region has been the most adversely affected with the epidemic (Figure 1)(13). Though being home to only 16.2% of the world's population, more than 54% of the overall number of people living with HIV

(PLWHIV) are inhabited by Africa (14) (13). Being home to more than 71% of the total number of PLWHIV, the Eastern and Southern African region of SSA, experiences the highest disease burden (15). Zimbabwe, in conjunction with six other countries accounts for more than 50% of the new HIV infections worldwide (13). Zimbabwe’s total population is 14.82 million, in which 62% of the population is aged less than 25 years (16) (17). Out of the total population of Zimbabwe (i.e. 14.82 million), 1.33 million people are living with HIV, with an adult prevalence of 13.3% (18, 19).

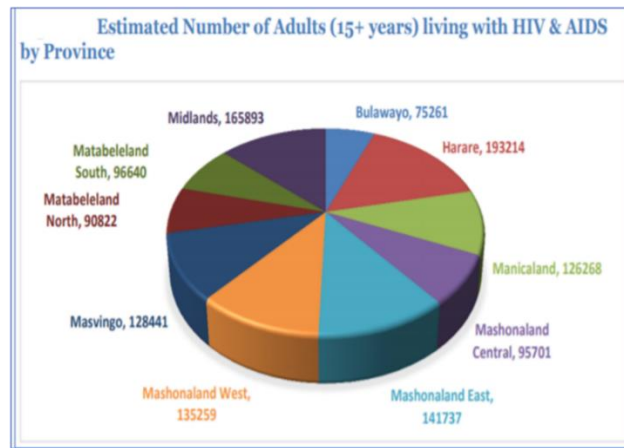
Figure 1: Global adult prevalence and distribution of HIV, 2018.



Source: Adult HIV prevalence (ages 15-49 years); UNAIDS, AIDS info 2019

Harare, the capital city of Zimbabwe and the largest out of the 10 provinces in the country, has a population of 1.54 million and bears the highest number of PLWHIV in the country (Figure 2)(20) (21). Additionally, the highest number of AIDS-related deaths were also reported in Harare, along with the greatest number of new child infections in Zimbabwe (21). Until recently, Zimbabwe documented one of the highest rates of HIV/AIDS infections in Africa, however, the number of HIV/AIDS-related deaths in the country have declined significantly owing to the strenuous efforts made by the government (22) (23). This noteworthy decline in the number of HIV-related deaths in Zimbabwe is ascribed to the monumental expansion and delivery of Anti-retroviral Therapy (ART) (21). Remarkably, in SSA alone, ART has prevented about 4.8 million deaths from 1995-2013 (24).

Figure 2: Provincial stats of adults (+15 years) with HIV/AIDS in Zimbabwe

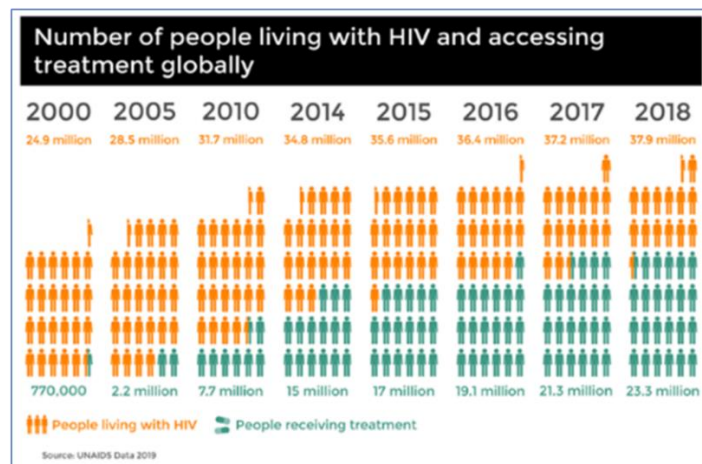


Source: Zimbabwe-HIV-Estimates-Report-2018 AIDS & TB programme ministry of health and childcare

1.1.3 HIV treatment (Anti-retroviral therapy)

Years of toiling and labour for formulating agents to treat HIV became fruitful in 1995 with the advent of HIV treatment i.e. Anti-retroviral Therapy (ART), which led to paramount advances in making HIV a manageable disease (25). ART is the regular and daily usage of a combination of HIV medicines, aimed at treating HIV (3). HIV is treated through agents called Antiretroviral drugs or Antiretrovirals (ARV's) (26). Although, unable to cure, ART has transfigured the façade of HIV from that of a fatal infection to a chronically manageable disease (3) (26). At present, PLWHIV on ART are anticipated to have near normal lives, comparable to those without HIV (27). The expansion of ART has enabled the therapy to be accessed by 23.3 million people out of the total 37.9 million PLWHIV globally (Figure 3).

Figure 3: Number of people receiving ART globally (2018)



Source: UNAIDS Data 2019

Notwithstanding the global availability of ART, Eastern and Southern Africa; the region hit hardest by the HIV epidemic, has a different monetary standing compared to the rest of the world (27). This is due to the fact that SSA is home to most low-income countries and financial feasibility of drugs is a major concern for the region, therefore, the HIV drugs in SSA must be fiscally feasible for these countries (27). In Zimbabwe, amidst the generalised HIV epidemic, ART was introduced in the year 2004, while until the end of 2016, approximately 900,000 people in Zimbabwe had access to ART (28) (19). The ART regimen employed worldwide for treatment naïve patients comprises of three ARV's from two drug classes (29). In Zimbabwe, the first-line regimen used comprises of a dual or triple therapy regimen (Table 1) (30).

Dual Regimen	Tenofovir (TDF) 300mg+ Lamivudine (3TC)300mg
	Zidovudine (AZT) 300mg + Lamivudine (3TC) 150mg
Triple regimen	Tenofovir (TDF) 300mg + Lamivudine (3TC) 300mg + Efavirenz (EFV) 400mg
	Tenofovir (TDF) 300mg+Lamivudine (3TC) 300mg+Efavirenz (EFV) 600mg
	Zidovudine (AZT) 300mg + Lamivudine (3TC) 150mg + Nevirapine (NVP) 200mg

Table 1: ART regimen in Zimbabwe

With the enormous escalation of ART programs, a treatment coverage of 88% is observed in Zimbabwe, wherein, the dissemination of international programmes like “*Treat All*” have enabled treatment access for nearly all PLWHIV in the country (13) (31). Similarly, at a global level, a decline in the worldwide HIV infections has also been observed, owing to the large-scale spread of ART and exclusive attention towards the low-income countries (32). Despite the multitude of challenges faced by these low-income countries, a substantial increase in the coverage of people accessing HIV treatment has been noticed in SSA (14). Countries like Zimbabwe are now delivering HIV treatment to people residing in the most distant and remote areas of the country, through various primary care clinics and hospitals (32). Consequently, in Zimbabwe, about 1 million people (i.e. 88% of the PLWHIV) now have access to HIV treatment and the decline in life expectancy has been reversed back to 61 years, through the successful nationwide implementation of ART (13) (23). These statistics depict the effectiveness of ART, particularly in the low-income countries like Zimbabwe.

1.1.4 Significance of Anti-retroviral therapy

In addition to the evident benefits of ART i.e. treatment and management of HIV, some of its multitude of benefits include, reducing HIV-related morbidity and mortality, resulting in increased life expectancy for PLWHIV, along with enhancement of quality of life (33) (34).

Due to the decrease in viral load (i.e. the amount of HIV in a sample of blood (35)), brought upon by ART, PLWHIV are able to live near normal lives (36) (37). Resultantly, it also reduces the chances of transmitting the virus onward, together with delaying the disease progression (38).

Having said that, a sizeable body of evidence indicates that, as a prerequisite, attainment of the benefits of ART is reliant on near complete adherence to therapy (i.e. 95%) (39) (25). In addition to CD4 count (test to measure CD4 cells in a sample of blood, indicator of patients' immune function and response to ART (40)), non-adherence to ART is another undeniable predictor of worsening of HIV into AIDS and ultimately death (41) (42). Although necessitated by many other disease states as well, adherence to treatment in HIV is more critical due to the multi-level negative impacts that result from non-adherence to its treatment i.e. ART (43). Despite the availability of numerous drugs for treatment of HIV, their benefits are dependent on patient's adherence to the treatment regimen, together with a sustained adherence over the passage of time (44). Notwithstanding this, the literature also testifies of the variation in adherence to therapy observed among different age groups (45). In HIV, considerably lower rates of adherence to ART have been ascertained among ALHIV, compared to that in the other age groups (46).

1.1.5 Age; a barrier in adherence to ART

As mentioned above, age is a crucial factor in adhering to treatment and since adolescents experience major neurodevelopmental and physical challenges, this age group is the most susceptible to treatment non-adherence (47). Adolescents living with HIV represent a vulnerable population among the PLWHIV, in whom significantly lower rates of adherence to treatment have been observed (48) (49). The numerous challenges faced by ALHIV in adhering to their treatment, result in poor treatment outcomes for this age-group compared to other HIV-infected people (50). Owing to the vital role played by age in adherence to ART, many studies have examined the effect of age on ART and have found that younger age is associated with decreased ART adherence (51). Non-adherence to HIV treatment has dire consequences like virologic failure, that not only endangers patient's health, but also induces drug resistance (52) (53). In addition, it also propels increased costs of treatment, together with warranting 2nd or 3rd line drugs (44). According to the National AIDS Council in Zimbabwe, approximately 35% of the people receiving ART are on 2nd line treatment, turning out to be uneconomical for the fiscally debilitated health system of Zimbabwe (54). In resource-stringent settings like that of

Zimbabwe, adherence to therapy is vitally crucial, as non-adherence may easily wipe out the existing, efficacious treatment options for PLWHIV (52).

1.2 Research Problem

The research gap of non-adherence of ALHIV to ART underscores the need to further investigate this phenomena (55). In SSA, a major share of the population is adolescents; ascribed as the future generation, a high rate of HIV/AIDS among adolescents may jeopardize national economies and societies (56). In countries like Zimbabwe, where more than 62% of the population is aged less than 25 years, the presence of obstacles like extensive poverty, political instability and civil struggles, further complicate life for ALHIV (57) (56).

ART has been monumental in transforming the fate of PLWHIV, however, the growth of perinatally affected children into adolescence generates new problems (58). The widespread distribution of ART has resulted in a rapid decline of HIV/AIDS-related deaths among all age-groups, thereby increasing their life expectancy, however, despondently, the death rates have remained constant in only one age-group; ALHIV(59). Unlike the other age groups where ART has decreased death rates, mortality rate among ALHIV in Africa has not observed a steady decline where AIDS-related deaths among ALHIV have increased by 45% (60) (59). Irrespective of the global decrease in AIDS-related deaths across all ages, appallingly, fatality rate among ALHIV rose from 18,000 deaths per year in 2010 to 41,000 in 2015 (61). Also, for ALHIV, in the year 2015, HIV was the second leading cause of death worldwide and the first in SSA (62). This high mortality rate in ALHIV is ascribed to their non-adherence to ART (63) (64). International organizations like the WHO have reasoned this failure to lack of provision of adolescent-friendly services and poor follow-up on adherence of adolescents to be the causative of these grave circumstances (65).

A latest study from Zimbabwe illustrated the ALHIV to be at a greater risk of treatment and virological failure (54). Zimbabwe, a Southern African country, with one of the highest HIV prevalence, even by 2017 had 1.3 million PLWHIV (66). Nonetheless, effective ART expansion approaches like “*End the AIDS Epidemic*” have enabled access to ART by nearly one million PLWHIV in Zimbabwe, thus, catalysing the national decrease in mortality due to HIV (23). With these figures in mind, Zimbabwe is on the course to attain viral suppression in 87% of its adults living with HIV (54). Surprisingly, in Zimbabwe only one age group; adolescents (age: 10-19 years) remains, in which the prevalence of HIV has continued to increase instead of decreasing like other age groups (28). In Harare, the capital city, the viral

suppression observed in adolescents in 2016 was only 44% (i.e. less than half of the adult rate) (54) (28). In the city of Harare, adults living with HIV gained an 88% viral suppression after 12 months on ART, whereas, the ALHIV observed only a 57% viral suppression (54). In a country like Zimbabwe, where massive scale-up programs for provision of ART exist and strenuous efforts for viral suppression are being done, these numbers suggest the dire need to examine the underlying reasons for adolescents' treatment non-adherence. Furthermore, in order to augment the efficacy of ART, one of the fundamental variables which can be modulated to increase HIV treatment efficacy is *Adherence* (67). Therefore, it is crucial to study adherence to treatment in adolescents who are living in a country like Zimbabwe, where HIV-related death rates are declining rapidly in all other age groups. Considering the urgency of the problem of treatment non-adherence among ALHIV, the International AIDS Society (IAS) and World Health Organization (WHO) have also urged to undertake research among ALHIV (68). Particularly, attention has been called to, assess reasons of treatment non-adherence among ALHIV and to propose effective strategies that will improve their adherence (68).

1.3 Research Question

A research question establishes the problem to be studied and also directs the methodology, thereby, aiming at assessing the ambiguity in the research problem (69). Particularly in healthcare research, research question defines a critical step, through which health of individuals and populations can be protected, restored or maintained (70). The study at hand is a two-fold study, wherein with regards to the above-mentioned research problem (Section 1.2), this study entails the following research questions:

1. *“What are the barriers to treatment adherence for ALHIV in Zimbabwe, from the viewpoint of the healthcare providers?”*
2. *“What can be the most effective strategies to improve adherence to treatment for ALHIV?”*

1.4 Aims and Objectives

Research aim refers to the purpose of conducting a research, whereas, research objectives explicitly denote the ways that help in underscoring the main issues in the research, for the attainment of aims of the study (71) (72). In view of the above-mentioned context, this research has a two-fold aim, First; to identify the reasons for treatment non-adherence among ALHIV and Second; to propose strategies for improving treatment adherence among these ALHIV.

This research anticipates comprehending the reasons of mortality among ALHIV, through the viewpoints of healthcare providers (i.e. HIV counsellors, nurses and doctors), working with ALHIV. It brings to light the fact that, in low-income countries like Zimbabwe, there lie less studies that have explored the above-mentioned subject from the perspective of healthcare providers, who function as facilitators and gatekeepers of the adolescents' HIV experiences. Therefore, in line with the 2017 research priorities set by IAS and WHO for ALHIV (68), the aim of this research is: *“To identify the barriers to treatment adherence among adolescents living with HIV in Zimbabwe and to develop effective strategies to increase their adherence to HIV treatment”*.

For the fulfilment of this aim, the following objectives are undertaken:

- Data will be gathered through insights of the healthcare providers, detailing the reasons behind treatment non-adherence among ALHIV in Zimbabwe.
- The collected data will be critically assessed and evaluated for identifying the most prominent reasons of treatment non-adherence among ALHIV.
- Recommendations will be made to propose effective strategies, to improve HIV treatment adherence among ALHIV.

1.5 Significance of the study

Adolescence is a critical phase of life between childhood and adulthood and being the focus of the HIV epidemic, these individuals will live the longest with the disease (59) (60). With the intention to deliver the peculiar needs of this group, it is necessary to delve into the barriers that prevent ALHIV from adhering to their treatment, especially in resource-limited settings (73). Healthcare providers, as mentioned above, are central to treatment adherence of ALHIV, therefore, views of the healthcare providers sought in this research will assist in putting forth effective strategies, for the fulfilment of research priorities laid down by the WHO (74) (75). Moreover, identification of barriers to treatment adherence among ALHIV, will facilitate in the formation of interventions, tailored to the needs of ALHIV, since the numerous existing adherence interventions are aimed at adults and data for ALHIV is noticeably scarce and deficient (76). Previous studies also highlight the dire need to formulate interventional strategies for improving treatment adherence among ALHIV, so as to improve their health outcomes and decrease their costs of healthcare (76) (77). The results of this study can assist public health policy makers, programmers and practitioners to formulate and modify interventions targeted at ALHIV for promoting a positive, social and behavioural change,

leading to reduction of HIV prevalence among ALHIV, and decreasing their vulnerability to HIV (77).

To summarize this chapter, the aforementioned information validates that HIV has been the worst epidemic the world has seen till now, claiming millions of lives. Since its inception in the 1980s, it continues to kill thousands of people in SSA. Zimbabwe, one of the countries in SSA with one of the highest HIV-death rates, has shown improvements in declining the HIV-related death rates, through an extensive national spread of ART. Nevertheless, adherence to treatment is still a major problem for ALHIV in Africa. ALHIV in Zimbabwe still have high rates of non-adherence to treatment unlike all other age groups in the country, in which death rates have declined smoothly. Decreasing the barriers to treatment adherence among ALHIV is necessary to attain the Sustainable Development Goals (SDGs) (Goal 3; ensuring healthy lives and promoting well-being at all ages), reducing health inequalities as well as, for improvement of treatment outcomes for this vulnerable population (78). Therefore, as recognized by the IAS and WHO, a dire need for studying the problem of treatment non-adherence and formulating strategies to improve treatment adherence among ALHIV exists (68).

Chapter 2: Literature Review

The purpose of this chapter is to lay the context of this research through the review of the literature, so as to gather information about the dilemma of treatment non-adherence among ALHIV, while focussing on Zimbabwe. The literature review addresses the problem of non-adherence to HIV treatment in ALHIV. It describes the relationship between treatment non-adherence and adolescents. Moreover, it examines the barriers to treatment adherence among ALHIV, that have been explored in the previous studies. Lastly, in this context, this chapter justifies the validity of healthcare providers as the fitting respondents for conduction of this research. In short, the literature review suggests that ALHIV still face numerous challenges in adhering to ART and there lie numerous prospects that can be amended to improve ALHIV's adherence to treatment.

2.1 HIV and ART; an overview

Infection with HIV leads to AIDS in the most severe stages of the disease (79). AIDS precipitates into the incremental, consistent deterioration and collapse of the immune system, predisposing the affected individual to fatal infections (80). Although a sexually transmitted infection, HIV can also be transmitted non-sexually, during pregnancy (to the foetus) and through breastfeeding, whereas, other means of transmission include, sharing of injection equipment e.g. needles (81). Starting from the emergence of HIV in 1980's, currently, HIV has spread throughout the world and infects people in every region, thereby taking the form of a pandemic from an epidemic, making it an unparalleled calamity (10) (82). The distinctive features of HIV have made it the most catastrophic of all diseases till now, such as the multiple routes of transmission, lengthy progression, resistance against effective vaccines and a lack of a cure to date (82). Presently, about 37.9 million people are living with HIV and tens of thousands have died due to AIDS-related illnesses, depicting its menace to the health and development of nations (14).

Globally, HIV has been declared as the second most infectious and fatal disease, however, for countries in the SSA, HIV is the leading cause of deaths of millions (80). Being the region hit hardest by this epidemic, SSA inhabits more than two thirds of the global number of PLWHIV, where Zimbabwe has one of the highest prevalence's of HIV in the region (14) (22). In Zimbabwe, the first case of HIV/AIDS was reported in 1985, when nationwide, about 119 HIV cases were recorded (83). Since that time, HIV has spread rapidly throughout Zimbabwe, majorly by heterosexual transmission (83). In 2018, the national number of PLWHIV was 1.3

million, the incidence rate was 2.79 and a prevalence of 12.7% was observed (18). CDC (Centres for Disease Control and Prevention) reports HIV/AIDS to be the top leading cause of death in Zimbabwe (84). The instantaneous spread of AIDS worldwide and its detrimental effects on humanity was followed by profound efforts to search for its treatment (85). The advent of ART converged the façade of HIV from an untreatable fatal condition to a chronically manageable illness (86). SSA observed a rapid spread of HIV treatment after tremendous efforts and funding from WHO and other international organizations, ensuring the extensive access of ART throughout SSA (87). The success of ART expansion programmes in SSA became evident after the year 2000 (25). The scale-up of ART has certainly been a groundbreaking success in global health (87). Despite the soaring levels of HIV in Zimbabwe, the widescale access and availability of ART in the country resulted in a significant reduction of mortality rates among all PLWHIV in Zimbabwe (88). At present, there are about more than 30 HIV treatment medications available, which are grouped together in nine categories, based on their mode of action against the virus (89). However, the type of HIV treatment regimen is based on the patient's individual needs and factors like probable side effects/interactions are also analysed before choosing a regimen (90).

The primary aim of ART is reduction of viral load to an undetectable level, nonetheless, this does not cure HIV (90). HIV drugs keep viral load in the body under control, thus, persistent intake of medications is necessitated (adherence), to maintain adequate drug levels in blood for facilitating fight against the virus (91). In the contrary scenario, missing doses of ART increases the levels of HIV in the body, leading to destruction of immune system and increased chances of drug resistance (92). Therefore, ART must be taken for a lifetime and clinical benefits are yielded only upon strict, high adherence to ART (i.e. near complete or 95% adherence to therapy). Nevertheless, the lifelong necessitation of HIV therapy makes non-adherence to ART a common issue among PLWHIV, risking the invalidation of benefits of therapy (25). The multi-factorial and dynamic process of adherence, raises considerable difficulties for PLWHIV in following-up drugs in the long-term (25). Therefore, maintaining high levels of adherence to ART has been noted to be a challenge across settings and populations and thus, has been studied greatly throughout HIV literature (93). The abundance of issues revolving around ART adherence make it an extremely difficult and complex task for PLWHIV, to achieve the required 95% adherence, for an indefinite period of time (25). The WHO defines medication or treatment adherence as the extent to which a patient's behaviour aligns with the healthcare provider's recommendations (45). Treatment adherence is a

necessary pre-requisite across many diseases and the increasing prevalence and detrimental effects of non-adherence on patient, society and treatment costs makes it a threat to health care (94).

2.2 Treatment non-adherence and Adolescents

ALHIV have well-documented poor rates of adherence to treatment in comparison to other age-groups, in addition to higher rates of mortality (95) (63). Therefore, as cited by literature, age has a substantial impact on adherence to treatment (96). Based on this, even though, from 2005-2012, the global number of AIDS-related deaths declined by 30% for all ages, a contradictory trend was noticed among the ALHIV (36). UNAIDS in their 2016 report (Ending the AIDS epidemic for adolescents, with adolescents) stated that from 2005 to 2015, AIDS-related deaths in ALHIV increased by 45%; the only age group to have shockingly experienced a rise in HIV-mortality in this period (59) (97). In 2016, 2.1 million adolescents were living with HIV and the ones newly infected were about 260,000 (60). Globally, 3 million adolescents are infected with HIV, out of which a striking 90% live in SSA (98). In 2016, 73% of the new HIV infections among adolescents were seen in Africa (99). Additionally, in SSA alone, between 2000-2014, HIV-related deaths among adolescents increased thrice, in contrast to the decline in mortality observed among other ages, thereby, making HIV the leading cause of adolescent mortality in SSA (100). According to estimates, in Africa, every hour, 26 adolescents become infected with HIV and these ALHIV also have well-established poor adherence to therapy (101) (63).

As adolescence is the developmental stage between childhood and adulthood, this phase presents peculiar challenges that impact adolescent's adherence to treatment (63). The vital physical and emotional changes in adolescence arise along with their keenness to explore relationships, norms, sexuality and economic roles (102). The characteristic features of this age-group include, decreased parental supervision, increased risk-taking and immature judgement (103). Moreover, with underdeveloped life skills and absence of financial independence, adolescents also have limited access to health facilities (104) (105). Furthermore, the cumbersome requirements of a chronic illness, necessitating life-long therapy is further challenging for ALHIV (105). ALHIV experience challenges pertaining to, psychosocial issues, heightened responsibility of therapy, reduced family support, resistance to authority, stigma of HIV and poor inclination to foresee repercussion of actions (106). These traits make adolescents particularly vulnerable to HIV and highly susceptible to poor adherence

to ART (64). Adolescents are at risk of HIV, firstly during childbirth (vertical transmission) and secondly during the liability brought upon in the second decade of life i.e. adolescence (horizontal transmission) (105). Adolescents are the focal point of the HIV epidemic and in many African countries the majority of population is youth e.g. in South Sudan 51% of the population is aged less than 18years (107). Estimates suggest that by 2060, the number of African children aged 10-24 years is expected to rise by more than 750 million (99). Therefore, with the current pace, new infections among ALHIV will certainly increase, while hampering this progress will have calamitous outcomes (85). Moreover, it is estimated that between 2016-2030, as many as 740,000 adolescents could be infected with HIV (60). Therefore, shifting the focus towards ALHIV is pertinent to fostering actions against HIV (108). Adolescents represent a heterogenous group, living in distinct settings, having dissimilar needs (109). Their reasons for not adhering to HIV treatment are also different from other populations, as their biological developmental progress and age increases their susceptibility to HIV (25). Sadly, in spite of the increasing numbers of ALHIV, specialized care and attention for this group has been scarce (110). In view of the above-mentioned literature and the global concern of treatment non-adherence among ALHIV, it is necessary to identify the factors effecting it (25).

2.3 Barriers to treatment adherence

Many studies have converged to the challenge of treatment non-adherence among ALHIV, despondently however, even after more than two decades of studies and research, adherence to ART among ALHIV still remains a challenge (39) (64). Although patients are central to taking medications as prescribed, many other factors also influence the medication taking behaviour of ALHIV (111) .

Personal attributes and age-specific traits of adolescents have been stated as hindrances to medication adherence in the literature. Forgetfulness, owing to increased socialization among ALHIV, due to which they forget to take medications, is a major concern and drug taking is also halted out of the fear of inadvertent disclosure while being with friends (112). Denial and anger due to HIV also poses a barrier in adherence (113). According to studies, domestic financial responsibilities creates imbalances in drug taking (114). Many adolescents also become demotivated and suicidal and stop taking drugs (115). Moreover, families mistakenly assume the child's maturity to manage drug taking, which may still be low due to developmental delays, consequently, adherence suffers (63). Because of the decreased parental supervision, the erroneous involvement of adolescents into drugs and alcohol also hampers

their capability to adhere to drugs (64). Adolescents' inquisitiveness towards relationships, early inaugural of sexual activity and young pregnancy, also hinders drug taking in some adolescents (20) (113). Cases of mental illnesses, like depression and behavioural disorders have also been reported to be notable barriers to ART adherence (116). During adolescence, the longing to seek independence from parents turns out to be a means of externalizing anger and resolving conflicts with parents, together with the inclination of risk-taking that leads them to non-adherence (113).

The most prominent barriers that emerged among ALHIV in the previously conducted studies in low-income countries noticed two major issues related to social aspects i.e. problems of disclosure and stigma associated with being known as HIV-positive. Previous studies have stated that disclosure was a significant barrier for ALHIV in adhering to treatment, due to the prevailing stigma attached with being HIV positive (117). Stigma takes various forms, ranging from being isolated in the society to feeling abandoned by family (64). This stigma inculcates feelings of secrecy, guilt and fear of being known as HIV positive, so these adolescents avert from medication taking (118). Additionally, stigma also creates problems in disclosing ones positive status to peers, partners and other family members as well, and adolescents refrain from taking drugs regularly (119). Moreover, the anxiety and stress of being rejected and discriminated, leads the ALHIV towards not taking medications (120). Family support is an important facilitator of adherence to treatment for ALHIV however, in cases where ALHIV do not have family support to remind and support them to take drugs during this challenging phase, adherence to medications is obstructed (118) (63). Further, family environment and change of guardianships for orphaned adolescents may also lead to hindrance in taking drugs (63). Also, stigma and disclosure, creates problems for ALHIV in school settings, the literature also indicates that adolescents have reported of being bullied and called names in school, especially those who live in boarding schools face considerable challenges due to lack of private spaces (121). As the adolescents do not have their private rooms to take medications, hiding medications from their peers and taking drugs on time is specially arduous for these ALHIV, therefore, they prefer not to take medications (118).

Furthermore, the other barriers that the adolescents face are linked to the economic and financial aspects of HIV treatment. Structural and economic barriers are cited in the literature, which include factors like increased costs of transport, limited access to food, as well as political instability (120) (118). Many studies have reported that regardless of the free provision

of ART, high costs of HIV-treatment deprive the adolescents to adhere to their treatment (122). One such cost is increased transport expenses, as the adolescents are financially dependent on adults, increased transport costs create hindrance in ALHIV's access to health facilities and adherence (123). Distance to the healthcare facilities is also reported as a barrier to adherence that leads to more transport costs, thus hampering drug taking (64). In addition, poverty is also a significant barrier that reduces ALHIV's access to health facilities and their ability to collect ART (124). Most adolescents cannot afford to pay for their transport to access drugs, the country's economic challenges exacerbate access to drugs particularly for ALHIV (125). The impact of poverty is also noticed in the ALHIV's inability to buy food for themselves (63). As most HIV drugs warrant food, the food insecurity; cited by many studies, especially in low-resource settings, makes drug adherence for adolescents difficult (126).

Research also illustrates barriers to adherence engendered by the healthcare facilities, since the usual clinic visits for drug collection may last an entire day, thereby leading to missed work (and wage) and schooling, therefore, the ALHIV avoid visiting the clinic (113). Moreover, timing of clinic appointments conflicts with the school timing of ALHIV, because of which they are unable to timely collect their medications, resulting in non-adherence (118). Others have also reported administrative problems like misplaced clinical charts, long queues and setbacks in public insurance paperwork, thereby, causing obstruction in initiation and adherence to ART (113). More factors associated to healthcare services such as, long waiting times at the clinics, erratic drug availability and quality of care delivered in the hospital settings also pose a barrier in forming a negative attitude towards drugs (95). Other studies report that the absence of a friendly doctor-patient relationship, reactions of doctors and poor attitude of the healthcare staff also impedes adherence, where access to healthcare is also a barrier (113). Additionally, some studies also report that distance to the health facilities and drug stock-outs obstruct the ALHIV in adhering to treatment (127).

Some studies also describe that treatment related factors are also a barrier to adherence (64). As treatment of HIV has to be taken diligently each day, the adolescents usually get tired and bored of taking their drugs (113). Pill burden, negative side effects, and having problems in transitioning from paediatric to adult services is also a challenge for some adolescents (63). Pill burden can be observed in many forms, either in the number of pills to be taken, their taste and taking drugs in different social settings (112). The drug formulation also forms a barrier because of the inability to swallow drugs and the bitter taste is used as an excuse by many

adolescents for not taking drugs (120). Research reports that the perinatally infected ALHIV, increasingly experience an exhaustion from the long-term commitment to ART, that decreases their interest in drug taking (128). Health providers report that the fatigue associated in dealing with HIV status and the lifelong duration of HIV treatment causes some adolescents to take prolonged breaks or drug holidays (129). Adverse reactions to ART also drive the adolescents away from medicines to prevent the occurrence of any side effects (113).

2.4 Healthcare Providers; an important context in treatment adherence

Adherence to ART among adolescents continues to be a significant challenge in the low-income countries (95). Even though a little progress among ALHIV has been made globally, nonetheless, attaining progress in the region struck most adversely with HIV i.e. SSA, is a dilemma for public health researchers (130). Additionally, it is evident that accomplishment of the United Nation's health-related Sustainable Development Goals (SDGs) and 90-90-90 targets for the year 2020 will be particularly challenging, in the population of ALHIV (130) (65). The literature verifies that till now, ALHIV face numerous barriers in adhering to treatment and have worse outcomes in the HIV care cascade (131). In each of the studies assessing barriers to treatment adherence among ALHIV, one common factor in nearly every study impacting adherence is the healthcare system: primarily, patient interaction with the healthcare provider (132) (133). Healthcare providers through their knowledge of disease, healthcare system and interactions with ALHIV, play crucial roles in supporting adherence (134). Moreover, the role of healthcare providers has been declared to be pivotal at every level of HIV treatment and particularly crucial for ALHIV (135). HIV healthcare providers (i.e. counsellors, nurses and doctors) support adolescents' good adherence (135). Health providers, particularly doctors and moreover nurses are essential when it comes to merging efforts to acquire better strategies to engage ALHIV in self-care. Being at a significant designation, these healthcare providers, are able to recognize the cultural and individual aspects of their clients, re-evaluating concepts and assessing each individual's barriers to care (136). Furthermore, nurses counsellors and doctors play pivotal roles in HIV care and treatment and being a part of the multidisciplinary HIV team, they help improve patients quality of life (137) (136). Counselling, on the other hand is a core element of HIV care, through which the vulnerable ALHIV are assisted with issues related to adherence and life (138). Therefore, the knowledge of these health providers (counsellors, nurses and doctors) is crucial, in relation to treatment of ALHIV. However, sadly, only a few studies have included views of healthcare providers when assessing adherence to HIV treatment (134). Literature suggests that healthcare providers are

the first health system representative and therefore, have a profound impact on ALHIV's involvement in care (139). Forming an integral part of the healthcare system, the WHO definition of treatment adherence relates no professional, other than the healthcare providers in adherence to treatment (4). Therefore, the literature verifies that the views of healthcare providers are particularly important in identifying barriers and proposing strategies for HIV treatment adherence among adolescents (140). Studies also suggest that providers experiences in implementing HIV treatment adherence strategies will give an insight into how HIV care can be improved and how systems surrounding adolescents can be strengthened to maximally support increased treatment adherence over time (139). This highlights the pressing and urgent need to design, implement, and test interventions among ALHIV, from the views of healthcare providers, that are effective in increasing HIV treatment adherence, to ensure viral suppression and decrease in adolescent HIV-mortality (130). Since healthcare providers have the greatest knowledge of HIV and ALHIV through constant interactions with them, therefore, their knowledge and insight can be of great use while recommending strategies for enhancing treatment adherence (134) (68) .

Chapter 3: Methodology

This chapter will describe the research design formulated to identify the barriers to treatment adherence among ALHIV and propose strategies for improving treatment adherence among this age group, in Zimbabwe. Research design entails the rational strategy and framework for collecting, processing and analysing data, wherein, research onion describes a comprehensive means to effectively design and organize a research methodology, giving a detailed account of the key steps to be achieved for assembling an effective methodology (141) (142). Therefore, in order to attain the research objectives, this chapter comprises of the elements of research onion i.e. research philosophy, research approach, methodological choice, time horizon and the details of data collection and methods of analysis.

3.1 Research Paradigm and Approach of study

In order to attain the objectives of this research, the first step in the methodology is to identify the research paradigm. A paradigm is an all-embracing philosophical or ideological perspective and belief system about the worlds' nature, which when employed in research, forms the basis of assumptions through which knowledge is produced (143). In the context of healthcare research, the paradigmatic positioning of a researcher examines comprehension of the nature of knowledge (epistemological view) and reality (ontological view) (144). An Interpretivist paradigm, aims at attaining a deeper understanding of phenomena in unique contexts (145). Therefore, in order to gain deeper insights into the complex phenomena of treatment non-adherence among ALHIV, this research will employ an Interpretivist approach, illustrating that the researcher will confirm the social construction of knowledge and subjective nature of reality (146) (147). As in most qualitative healthcare research, in terms of methodological approach, an Inductive approach shall be implemented for collection of qualitative data. Inductive approach enables the researchers to institute the research with the least pre-conceptions, generating patterns relying on theory, thereby, facilitating the formation of theory from the emergent data (148). Overall, aiding in identifying barriers to, and forming strategies for improvement of treatment adherence among ALHIV in Zimbabwe.

3.2 Research methods

Research methods denote the verified procedures and techniques used, through which data concerning the subject of research is collected and analysed (149). Research methods are of two types; Qualitative and Quantitative, where the qualitative method, involves a naturalistic approach and delves into the subject. The qualitative method employs an interpretive approach,

intending to interpret and discover deeper meanings of phenomena through associations and views of the people (150). Contrarily, quantitative approach deals with numerical data through usage of statistical techniques (151). The quantitative HIV research conducted till now has failed to extensively explain the contexts in which the protective and risk factors around HIV function, and has been restricted in its ability to impart community, structural and individual level interventions (152).

3.2.1 Qualitative research in HIV

Qualitative research in HIV is capable of analysing multiple factors while enhancing the researchers' ideas behind the elements, working conjointly to form the socio-cultural meanings of sexuality, resilience and health (152). The lived experiences facilitate in establishing rich descriptive interpretations, thereby underscoring the socio-cultural, structural, contextual and political aspects of HIV, aiding in a thorough understanding of the disease (152). Therefore, to understand the reasons for treatment non-adherence among ALHIV in Zimbabwe and for proposition of strategies to increase adherence, this study employed the qualitative method, aimed at the vulnerable HIV population of adolescents.

3.3 Data collection

3.3.1 Study site

The study was carried out in the city of Harare in Zimbabwe, at three health facilities; Harare Central Hospital, Parirenyatwa Hospital and Rutsanana Poly Clinic. In addition, healthcare providers were also recruited from the BREATHE trial (study of the BRTI; Biomedical Research and Training Institute) in Zimbabwe. Zimbabwe is situated in the southern part of Africa, surrounded by countries like Mozambique and South Africa (16). The healthcare system of Zimbabwe continues to suffer major set-backs due to poor governance, socio-economic problems and political influences and other challenges like unprecedented inflation and brain drain of its health professionals (153). The reason for selecting Zimbabwe as the study site of this study is that the country is adversely affected greatly by HIV, owing to which even till 2017, the number of PLWHIV was 1.33 million, wherein the capital city of Harare bears the greatest burden and rate of HIV infections (21) (18). Moreover, the greatest number of new HIV infections were also observed in the capital city (21), urging the need to explore reasons for the high treatment non-adherence among ALHIV in Harare.

3.3.2 Study population

The participants for this research were healthcare providers who had experience in working with ALHIV. A total of 18 healthcare providers, involved in the care of ALHIV in different capacities were recruited, out of which nine were HIV counsellors, six of them worked as nurses, while three were medical doctors (For participant demographics, see Appendix I: Table 2). In view of the aim of this research, insights regarding the phenomena of treatment non-adherence among ALHIV were obtained from healthcare providers, since they are the most knowledgeable about the barriers to ART adherence in ALHIV, so as to propose effective strategies for improvement of treatment adherence. Counsellors; the health providers interacting most intimately with ALHIV through counselling sessions, manage adolescents everyday by listening and resolving ALHIV's treatment-related and life challenges, thus have the greatest knowledge on barriers to treatment adherence among ALHIV. Whereas, nurses are the primary deliverers of HIV treatment, moreover most clinics in the country are run by nurses, therefore, the daily encounter with ALHIV deepens their insights and knowledge on aspects of their treatment. In the HIV care cascade in Zimbabwe, medical doctors deliver care through their close, direct connection with ALHIV and facilitate enhanced adherence to HIV treatment for ALHIV, through consultation and understanding of adolescent-specific needs. Therefore, the number of providers chosen for this study is representative of the healthcare providers' role in HIV treatment, in descending order of their experience with ALHIV. A majority of the studies assessing ART adherence have focussed on the views of patients, while neglecting the views of healthcare providers (154). Whereas, healthcare providers are the preliminary functionaries of the healthcare system and the first point of contact in the treatment of ALHIV. Healthcare staff function as facilitators and gatekeepers of ALHIV and help formulate the adolescents' experiences towards HIV treatment and care hence, having a close relationship with ALHIV, they formulate the most suitable sample for fulfilling the aims of this study (154).

3.3.3 Sampling strategy

Entailing the most critical stages of research design, sampling is defined as the process of selecting a portion of things from a predetermined population, intended for inclusion in the study (155). As this research is qualitative in nature, purposeful sampling; the most extensively used sampling method was employed, for an efficacious understanding and selection of information-rich participants (156). As opposed to probability sampling, purposeful sampling involves identifying the most knowledgeable and experienced informants with regards to the topic to be studied (157). Furthermore, maximal variation sampling technique of purposeful

sampling was employed for recruitment of interview participants. This technique enabled the gathering of a wide range of experiences and views from the information-rich participants i.e. HIV counsellors, nurses and medical doctors. As the primary researcher was new to the city of Harare, the participants for data collection were allocated and sampled with the help of the local supervisor.

3.3.4 Research Instrument

This research used semi-structured interviews as the instrument for data collection. The in-depth, face-to-face interviews were directed through usage of semi-structured interview guide. A semi-structured interview guide contains an introductory section related to the topic and a list of topics and questions, along with the recommended probes and facilitates in guiding the conversation of the interview through the open-ended questions (158) (159) (For the interview guide of this research see Appendix II).

3.3.4.1 Interview Guide

Semi-structured interviews are in-depth interviews, wherein interviewees respond to several open-ended questions (160). The open-ended format of the semi-structured interview enables the accumulation of an exhaustive discernment of participant beliefs, thoughts and experiences on the subject matter (158). Healthcare research employs semi-structured interviews as the most common source of data collection, involving a flexible research protocol, enriched through probes, follow-up questions and comments, adapted in accordance to the context, through usage of an interview guide (158). The interview guide for this research was established keeping in mind the aims and objectives, as well as the inductive approach of the research, whereas a review of literature also assisted in formulating appropriate topics in relation to the primary study topic. Additionally, the interview guide was modified and altered through discussion with the research supervisors, that aided in adapting the document according to the needs of the subject under study. The interview guide started with the general experiences and views of the healthcare providers regarding HIV among adolescents and the overall views of HIV in Zimbabwe. While questioning and probing, a neutral tone was ensured so as to not influence/bias the respondents' views (161). During the conduction of all in-depth interviews, funnelling technique; employing introductory questions leading to the interview guide's central topic was used (161). The introductory questions led to the main subject matter, inquiring about topics related to treatment adherence of ALHIV in Zimbabwe, and their distinct nature regarding treatment adherence. On further probing and questioning about issues of

treatment adherence, a variety of answers were generated, that illustrated and identified reasons for treatment non-adherence of ALHIV in Zimbabwe, thereby, identifying areas to propose effective strategies for increasing adherence to treatment.

3.3.4.2 Study Period and conduction of Interview

Bearing in mind the time constraints associated with this research, and the nature of the study, like most studies in healthcare, this study was cross-sectional, that implemented interviews as the data collection method to understand the participant experiences (162). From August to October 2019, the primary researcher conducted 18 face-to-face in-depth interviews with the healthcare providers. The interviews lasted from 35-90 minutes (average 62 minutes) and were conducted at a private place, so that the participants could express their views unresistingly. Most of the interviews were conducted at the BRTI office in a private place, while the interviews conducted at the hospitals and the polyclinic were carried out in a place where there was no one around, to avoid any disruption during the interview. Complete information regarding the research aims, objectives and nature of study was explained to participants through the Participant Information Sheet (PIS) (see Appendix III). Written consent was obtained from each participant prior to conduction of each interview; with a detailed explanation of the study and answering of any participant queries (see Appendix IV). All information pertaining to the research participants was handled confidentially, moreover, participants were assigned codes while giving their reference quotations to protect their identity. All information of the research was stored in a password protected computer to prevent any unauthorized access.

3.3.4.3 Data saturation

Data Saturation directed the number of interviews to be conducted as well as the information present in them, which is an established practice for cessation in collection of new data (163). The sample size of purposefully collected samples in health science research is assessed by data saturation (163). Data saturation centres on the informational amount of data (i.e. interviews) required, till cessation of emergence of new data i.e. informational redundancy (164). After the 15th interview, no new data emerged, then the primary researcher judged that saturation had been achieved in data collection. However, three further interviews were conducted by the primary researcher to confirm and validate the assessment of having attained data saturation (165). Additionally, after data saturation, probing was continued until the assurance that an exhaustive understanding of participant perspectives was achieved (166).

3.4 Data Analysis

Data analysis involves the process of thoroughly organizing interview transcripts for enhancing understanding on the phenomena of interest (167). It comprises of classifying and coding the data, identifying essential components and patterns, and drawing meaning from the data (156).

3.4.1 Selecting qualitative thematic analysis

Majority of the qualitative data exists as rich, in-depth and contextual information (168). In order to gain insightful information from this rich data, it is pertinent to analyse the data comprehensively. This research employed Thematic Analysis (TA) as the method for qualitative data analysis, described as the identification, organization, analysis and description of reporting themes that emerge from data (169). The strength of thematic analysis lies in its ability to facilitate the researcher to take-on a well-structured methodology for data-handling and formation of reports that are indispensable in summarizing the essential components of large data (169). As this research employs an interpretivist approach, therefore, TA was deemed as the appropriate method to identify key themes and address the research question (170).

3.4.2 Conducting thematic analysis

Thematic analysis in this study was conducted in accordance with the six steps to qualitative inductive thematic analysis, as outlined by Braun and Clarke 2006 (171). Firstly, familiarity with the data, by transcribing the interviews and then reading (and re-reading) the transcripts and/or listening to the recordings. Secondly, coding of data was done by formation of concise labels for important and relevant data features linking to the (broad) research question, thus directing the analysis. Themes were searched, reviewed and named, so as to manifest a compelling story about the data. Finally, writing-up; comprising of intertwining the analytical description and the (vivid) data extracts to express to the reader a comprehensible and convincing version of the data, in relation to the current literature (For detailed explanation of the six-steps of TA employed in this research see Appendix V: Table 3).

3.5 Trustworthiness

Lincoln and Guba cited criteria for ensuring trustworthiness in a qualitative study. Trustworthiness denotes the researcher's capability of critically appraising each decision in the research (172). In this research, constantly checking the adequacy and accuracy during procedures of data collection and analysis, elicited the researcher's integrity (For these criterion

employed in this research see Appendix VI: Table 4). Nevertheless, this study used iterative, reflective process, which allows for inductive viewing of the existing literature (171). Additionally, thematic analysis also provides consistency and accuracy in results.

3.6 Ethical Approval, Consent and Confidentiality

In accordance with the ethical principles for conducting research and for protection of the rights of the research participants, ethical principles should be applied and adhered throughout the research (173). In view of this, principles of beneficence and respect for persons were consistently abided all through the research. Appropriate ethical approval from the regional ethical committee and that of the study site was obtained prior to commencement of the study. This study was conducted under the ethical approvals of the BREATHE Clinical Trial in Zimbabwe (see Appendix VII). Additionally, ethical approval was also sought from the Regional Committee for Medical Research Ethics (REK), in Norway (Reference number: 34232). Moreover, written consent was also obtained from participants, prior to conduction of interviews as described above (Section 3.3.4.2).

Chapter 4: Results

This chapter will present results of the study obtained after completion of TA from 18 in-depth interviews with participants. The main objective of this research was to understand the barriers leading to treatment non-adherence among ALHIV, in Zimbabwe and to propose effective strategies for improving their treatment adherence.

4.1 Presentation of results

In light of the research question, thematic analysis of data generated four themes and nine categories, that represented the barriers to treatment adherence among ALHIV. Themes are described as the essence or meaning of the narrative throughout the data, while categories depict the accumulation of similar data (174). For a comprehensive description of themes, categories, codes and respective quotations according to TA (see Appendix VIII: Table 5). The generated themes and categories together with illustrative quotes are presented as follows, for which, codes were assigned to ensure participant confidentiality.

4.2 Theme 1: Social barriers to treatment adherence

Social barriers comprising of socio-cultural and socio-economic factors, emerged as the most diverse barriers, deterring the treatment adherence of adolescents at numerous levels. At first, the prevalent socio-cultural issues of faith healers and traditional healers (Sangoma) have a negative impact on treatment adherence of adolescents, as stated by respondent R04:

...“we have a proliferation of faith healers, those are giving off problems and you know adolescents normally they want to find escape route, someone said I’ve prayed for you, you no longer have the virus, then they would be happy. Yes! I’m healed, I’m free from taking drugs”...

Another respondent R07, also said:

...“some they say: I was told to stop the medication from the church, some they say we went to see the Sangoma’s and they gave us the concoction and I’m now HIV negative”...

Additionally, for HIV; a sexually transmitted disease, the respondents specified that considerable stigma and discrimination still exists in the society, especially for ALHIV. Societal stigma leads to intolerance and unacceptability for ALHIV and causes problems for the adolescents, in disclosing the HIV positive status to their partners, peers and families, which greatly affects the way the adolescents adhere to treatment. As respondent R07 exclaimed:

...“people still have that strong strong strong stigmatization of the disease. So, it’s one of the biggest biggest challenges, where stigmatization would really lead to non-adherence and adolescents would defaultall those things affect how young people take their drug”...

Adding to the issue of stigma, another respondent R02 also claimed:

...“disclosure takes many forms, the need to disclose makes problems disclosing to other family members, friends, teachers, I ask some adolescents and they talk about stigma and discrimination”...

Importantly, family support was also another crucial factor in determining adherence to treatment for ALHIV. Most of these adolescents are orphaned due to HIV, they live with a caregiver/foster family and the respondents denoted that lack of support from families and stressful home environment prevents ALHIV from adhering to treatment in majority of cases, like testified by respondent R11:

...“they don’t have family support, they live with relatives who don’t like them, who stigmatize them who actually don’t support them. So, at the end of the day they probably decide to say, why should I take the drugs?”...

Another respondent R09, while talking about family support said that:

...“adolescent’s drug taking can be dependent on an adult person who may not be supportive, the adherence aspect also relates to the family support”...

Lastly, the socio-economic problems created by the economic situation in Zimbabwe have led to poverty and a decrease in the purchasing power due to the prevailing poverty and unemployment, as a result of which adolescents cannot afford to pay the user fee at the hospitals. As said by respondent R15:

...“the adolescents are unable to afford the money to visit the hospitals”...

Another respondent R12 stated:

...“because of consultation of 5\$, they cannot afford the money to go to the GP”...

Another issue due to socio-economic problems is that, due to poverty the adolescents are unable to buy food for themselves, and food insecurity directly impedes treatment adherence, as mentioned by respondent R08:

...“I think this has to do with their social life, like when there’s poverty, there’s no food to take before their medication So, the best thing that they can do is not to take the medication”...

The above-mentioned barriers depict how the socio-cultural and economic factors affect the treatment adherence of ALHIV not only at social level, but also by the healthcare system, which is discussed below.

4.3 Theme 2: Healthcare system barriers to treatment adherence

Healthcare system has a major part in the treatment of ALHIV and impacts their treatment adherence. The three ways through which healthcare system serves as a barrier in adherence to treatment of ALHIV are through problems at levels of healthcare management, healthcare functioning and healthcare providers. Firstly, the poor management of the healthcare system has led to nationwide shortages or insufficiency of all drugs at the healthcare facilities, including ARV’s. As respondent R10 verified:

...“they have shortages of drugs, what they do when they have ART shortages, because they can give up to 3months supply but when there are shortages, they will give maybe two-week supply”...

Another respondent R13, also mentioned the shortage as:

...”at times you find that some of the ART drugs are not available”...

Secondly, poor functioning of the healthcare system is barring ALHIV from accessing the healthcare facilities. These problems in the functioning have stemmed due to the decreased financing and poor funding towards the public healthcare sector by the governmental authorities. As a result, the user fee for the healthcare facilities is increased, which has further decreased the ALHIV’s access to health services, resulting in their inability to collect medicines and non-adherence to treatment. A respondent R02 stated the same as:

...“the user fee, because I know it’s one of the deterring factors for adherence”...

Respondent R13 also said that:

...“I think user fees are a barrier definitely and these have recently been increased as well”...

Thirdly, the economic downfall of Zimbabwe has led to many problems in the healthcare system and some major consequences on the healthcare providers. Most of whom have left the country in search of better work opportunities, resulting in healthcare staff shortage in Zimbabwe, this indirectly influences the treatment adherence behaviour of ALHIV, as mentioned by respondent R09:

...“I think it’s the issue of economic hardships in Zimbabwe, even the hospitals and the city health, their employment has gone down”...

The attrition of healthcare providers from the healthcare system has led to numerous consequences for the healthcare providers who have to work in poor conditions, with much lesser staff than the number of patients, in overcrowded clinics, where they do not even have the time to listen to the patients, as exclaimed by respondent R14:

...“its unequal (the workload), it’s just too much, you can tell that the nurse is just overwhelmed”...

Another respondent R10 also added:

...“They come to the clinic, they won’t even have time to listen, their benches are full, they need to clear them , clear all the clients. So, ratio is not good, I think it’s the issue of ratio of staff and people”...

Due to the increased workload and inability to perform their duties, the healthcare providers are over-whelmed by the amount of work and are not able to deliver quality care to the ALHIV, reiterated by respondent R13 as:

...“when the provider is ban-out, it affects everything, yeah, how can you treat a patient if you feel ban-out, when you are affected all over psychologically you cannot concentrate, you are strained, you cannot give quality health”...

The respondents also stated that the healthcare providers are sometimes also angry with the adolescents over petty issues and this severely impacts their adherence to treatment as the adolescents then avoid going to clinics for their treatment; a point mentioned repeatedly by the respondents, as said by R08:

...“one of the reasons why adolescents don’t go to the clinic is because of the attitude of the nurse”..

Respondent R12 also exclaimed:

...“And it’s mostly about the healthcare provider making them feel bad about themselves, yeah. That example of they’ll be cross with me if I tell them I haven’t taken the tablets. So yes, the adolescent’s perceptions are that they’ll be punished, or they’ll be shouted at, they sometimes say, I come, and I get told by the nurse you missed your appointment you have to come back next week. So, that sort of behaviour, some of the healthcare providers put on barriers, to try and punish the kids, which is shocking”...

The barriers from the healthcare system affect treatment adherence by decreasing ALHIV’s access to the healthcare facilities, through unavailability of medications, directly and indirectly influencing their adherence to treatment and through the attitude of the healthcare providers, who are judgemental and condescending towards these ALHIV.

4.4 Theme 3: Individual barriers to treatment adherence

Individual barriers to treatment adherence comprise of the disease-oriented barriers in adolescents, which are their own characteristics that impede adherence to HIV treatment. The respondents have stated that factors related to adolescent’s disease state i.e. HIV positive status create feelings of anger, bitterness and frustration among these adolescents, towards their parents, family and health providers. This is mostly due to only one child in a family being HIV positive, which creates feelings of inferiority and being different from their siblings. As stated by respondent R11:

...“sometimes some of their siblings would be HIV negative so then, they would say, uhh I would be bitter about my parents, even those siblings, so that bitterness would actually drive them not to take their medications”...

Another respondent R13 said that the ALHIV are bitter towards their parents for inflicting the disease upon them and thus, have a lot of anger in them:

...“they may start hating the parents, it is very difficult, and they are also very bitter about being HIV positive because they say they are innocent, they didn't do anything to get the disease”...

Moreover, the issue of non-disclosure of HIV positive status to the adolescent by the family or health providers, also gives rise to feelings of resentment and an attitude of non-adherence to treatment, like mentioned by respondent R02:

...“there’s a lot of resent and anger towards these adults, towards the healthcare providers for not being open.... I think when it’s done poorly it has big impact on how somebody adheres to drugs”...

Another respondent R10 also stated:

...“also, some felt you know let down by not being told the truth and just that anger you know yeah”...

Another important disease-oriented factor that drives the ALHIV away from treatment is the inability to see any future life prospects, whether its education, relationships or professional life. The lack of future opportunities makes them hopeless towards their life and they become de-motivated to adhere to their therapy and in most cases become suicidal. Respondent R05 verified it as:

...“and some of them they have suicidal attempts, so they just feel, what if I stop it and I die, because they.. some of them are hopeless, they feel they have lost their self-esteem”...

Respondent R01 also corroborated this as:

...“they see a bleak future, so it’s kind of like what’s the point why I should bother”...

The individual barriers are developed in these adolescents after being diagnosed with HIV, and their inner turmoil and emotional state is depicted through feelings of anger and bitterness towards everyone, a consequence of which is non-adherence to treatment.

4.5 Theme 4: Medication barriers to treatment adherence

In view of the respondents, factors related to the medications themselves may also act as barriers to treatment adherence. These barriers entail those that are related to the HIV treatment regimen and the ones that relate to the ART pills. HIV treatment is treatment for life, and adherence to therapy is insisted by health providers, at all times. Therefore, the need to take medications every day, for the rest of life is a daunting aspect of the HIV treatment, faced by ALHIV. The need to take medication regularly for the entire life seems cumbersome to these

adolescents and facing the problem of treatment fatigue, they do not adhere to their medications. Respondent R16 described this as:

...“I’ve felt that treatment fatigue is something, and it’s not surprising you know if you’re diagnosed with HIV since you were 4, you’ve been taking your tablets”...

Moreover, participants believed that the perinatally infected adolescents who have been taking the medication since a long time face an increasing problem of treatment fatigue as stated by respondent R12:

...“Because you’ve been doing it for so long and you’re like I’m done! Sometimes it’s just, I don’t wanna do it anymore”...

Secondly, the problems that adolescents encounter with the pills are those that are related to their large size, which makes it difficult for them to swallow, as the dosage forms are not age-friendly, therefore, ALHIV do not adhere to their treatment. Respondent R08 said:

...“even the size, the size of the pills, some complain that ahh they’re too big I can’t swallow them”...

For some adolescents, pill burden i.e. the number of pills to be taken is also a burden, as said by respondent R15:

...“there are times that they say, the number of pills and the size of the pills gives difficulty in adhering to treatment”...

Lastly, the problem of side effects of pills is also a barrier to treatment adherence. Although the respondents stated that before the initiation of therapy, the adolescents are given appropriate information and guidance on the possibility of having side effects and the guidance to not stop the medication if it occurs. Still, the adolescents fail to comply to the health providers instructions and stop their treatment. As respondent R11 stated:

...“They would be knowing the side effect and you’d have explained to them, that we are weighing the side effects against the benefits right and we have found that the benefits are more than the side effects, but still they stop”...

Respondent R02 while talking about side effects and non-adherence said:

...“They google out the side effects of the drug, then they say ahh I’m not going to take the drug because it is going to have this this this side effect”...

In summary, the results presented in this section have enabled the identification of barriers at various levels of treatment adherence among ALHIV, from the viewpoint of the healthcare providers. The gathered data was analysed, coded and characterised accordingly into themes, categories and codes. Importantly, the most common reasons for the adolescents to not adhere to their treatment according to this study were the social barriers. Particularly the issues of stigma and discrimination and un-intentional disclosure among peers, school friends and families, that abstain the ALHIV from adhering to their treatment. Additionally, the multiple levels of healthcare system barriers specially attitude of the healthcare providers is the second most important barrier contributing to treatment non-adherence of ALHIV, followed by the individuals’ bitterness, anger and frustration and the pill related factors in the medication barriers.

Chapter 5: Discussion

This chapter will elaborate the results obtained from interviews with the participants, subsequent to the thematic analysis of the collected data. Moreover, it will also elucidate the four themes discovered through this research and will facilitate in understanding these themes in light of the inter and intra-relationship between the hence identified barriers. Lastly, in accordance with the aim of the study, this chapter also proposes effective strategies to improve treatment adherence among ALHIV, after elucidation of the barriers identified by the healthcare providers.

The results of this study uncovered four themes relating to the barriers, that lead to treatment non-adherence among ALHIV in Zimbabwe. These four barriers in descending order of their influence on treatment adherence of ALHIV are Social, Healthcare, Individual and Medication. The four themes are sub-divided into nine categories (termed as factors), that are comprised of elements which function to generate the phenomena of treatment non-adherence among ALHIV. Out of the four barriers identified, Social barrier emerged as the most prominent and over-arching barrier that affects the treatment adherence of ALHIV in multiple ways. Subsequent to which, the healthcare barriers, individual barriers and medication barriers exist. The subsequent paragraphs will illustrate these four barriers, their corresponding categories and the mechanisms through which each of them leads to treatment non-adherence among ALHIV.

5.1 Social barriers to treatment adherence

Society forms a major part of the adolescents' life, influencing it through multi-faceted aspects of culture, norms and attitudes (175). Therefore, the relations that the adolescents have with their social sphere i.e. family, friends and society, all play a significant role in their adherence to treatment (176). Social barriers had a huge impact on the treatment adherence of ALHIV and were majorly comprised of socio-cultural and socio-economic factors. These factors were formulated by a multitude of elements like religion/faith healing & traditional healing, social ban (stigma, discrimination, taboos) and family attitudes in the socio-cultural factors, while poverty, increased transport costs and food insecurity, were included in the socio-economic factors.

5.1.1 Socio-cultural factors

Socio-cultural factors influence societal thoughts and behaviours, impacting the perceptions of health, illness and health seeking behaviours, in addition to formulating the native religious practices and taboos (177). Socio-cultural factors, as revealed through this research, have a deep impact on various social aspects of an adolescent's life, that in turn influence how they cope with their faith, culture, societal and familial relations, along with an HIV positive status.

5.1.1.1 Religion/Faith healing & Traditional healing

Religion is the conventional organization of sacred beliefs, establishing the fundamentals of community life and dictates the ethical beliefs around sexuality within societies (178). Results predicted that in Zimbabwe, religion/faith healing and traditional medicine had a great impact on the beliefs and attitudes of the society. Results verified that in African culture, these religious beliefs about sexuality also play important roles in generating societal stigma, intolerance, discrimination and unacceptability for ALHIV, through the sinful accusations made on these adolescents as being morally deviant and promiscuous. As a result, the ALHIV are looked down in the society, which creates tremendous problems throughout their HIV treatment cascade for adhering to treatment. Moreover, as adolescents are adult-dependent, the treatment of many of these adolescents is interrupted by adults in the family, on instruction from faith healers (mostly Pentecostal churches), who falsely claim to heal HIV, resulting in numerous cases of adolescent deaths. Secondly, in Harare, the Shona people (the majority ethnic group) particularly seek help from Sangoma's or traditional healers who claim to liaise with ancestral spirits through divine connections for amelioration of diseases (179). It was revealed through the interviews that native similarities in beliefs and practices of traditional healers, incline people towards them, rather than preferring the allopathic HIV treatment. Furthermore, in African culture, the elders of a household make all decisions, therefore, if the elders in an adolescent's family opt for traditional medicine, ALHIV's treatment will inevitably be ceased. Previous studies confirm the negative impact of faith healers and traditional medicine on adolescents' treatment adherence (180).

5.1.1.2 Social ban (stigma, discrimination, taboo)

Social ban refers to the socio-cultural stigma and discrimination in the society, specially pertaining sex, sexual activities and socio-cultural misunderstandings about the spread of HIV (181). Findings reveal that although efforts have reduced stigma for PLWHIV, however, considerable stigma still exists for the ALHIV. The reason for stigma is that HIV is a sexually

transmitted disease and despite the awareness, the sexual aspect of this disease cannot be omitted. Owing to this, adolescents were found to face extensive problems in each aspect, throughout their life, which greatly impacted their adherence to treatment. Stigma and anxiety of being discriminated, arouses resistance and fear of disclosure among the adolescents. As a result, the lack of disclosure eradicates support for these adolescents, which is highly needed during this phase of life. These instances of social isolation were encountered by ALHIV among both, families and peers, also, the intentional abstaining from drug taking is preferred by ALHIV to conceal the HIV positive status. Additionally, in boarding schools, the lack of private spaces and stigma leads to missed doses of drugs. The results showed that adolescents hesitated visiting clinics as well, due to the fear of unintentional disclosure and abstain from clinic visits for drug collection. Similar findings have been reported by earlier studies indicating the negative impact of stigma, discrimination and disclosure issues on ALHIV's adherence (118).

5.1.1.3 Socio-Familial beliefs and attitudes

As indicated by results, family environment and support from family was a significant factor in ALHIV's adherence to treatment. Family has been asserted as the basic unit of organization and plays a critical role in the African culture, connecting individuals with society (182). However, results revealed that many parents out of the fear of stigma, being socially rejected, blamed and hurt, did not disclose the child's HIV status, which later created mistrust within families and a reason of adolescents' non-adherence. As an adolescent's need for family support is heightened during this difficult phase of life, such instances of mistrust and lying eradicated the support and coherence among families.

5.1.2 Socio-economic factors

Socio-economic factors denote the way social and economic factors affect each other in communities (183). The various aspects of socio-economic factors that negatively affect the adolescents' adherence are discussed as under.

5.1.2.1 Poverty

The findings discovered that poverty has a multi-dimensional effect on the adolescents' adherence. The adolescents are financially dependent on adults because the opportunities of employment and financial stability in Zimbabwe for adolescents are close to none. Due to which, in cases of unavailability of money, the adolescents are unable to collect their drugs or visit healthcare facilities. Moreover, this situation is exacerbated, as inflation in the country has

increased the costs of daily commodities as well as costs associated with treatment, therefore, such critical financial scenarios result into the adolescent's inability to cope up with their treatment.

5.1.2.2 Food insecurity

An aspect of poverty underscored by the results is, the inability to buy food due to the lack of financial resources. Food is an important pre-requisite for most ARV's. However, in reality, the poverty and socio-economic circumstances of these adolescents avert them from being able to buy food for themselves. The recent cyclone Idai (one of the most devastating tropical cyclones suffered by Zimbabwe, causing widespread devastation) has also created massive shortages of food for the people living in Zimbabwe, that has also worsened the drug taking capability of many such adolescents. Therefore, the lack of food directly results in not being able to adhere to treatment.

5.1.2.3 Increased transport costs

The socio-economic problems of Zimbabwe, primarily recession and increased rates of inflation have greatly resulted in worsening of the living situation for the residents, as it has also wiped away jobs and working opportunities of many people in Zimbabwe. Therefore, earning money is no less than a struggle in the current socio-economic scenario of Zimbabwe. An aspect linked closely to adherence of therapy for the vulnerable ALHIV is the increased cost of transport, due to which the adolescents are unable to visit the healthcare facilities for drug collection.

5.2 Healthcare system barriers to treatment adherence

Encompassing the healthcare providers, healthcare institutions and resources that provide healthcare services to people (184). Healthcare system is the foremost player in the provision of treatment and greatly impacts how ALHIV adhere to treatment. Healthcare barriers are made up of three factors; healthcare system functioning, management and staff/providers. All of these factors act in varied multiple ways to hinder treatment adherence of ALHIV, which is discussed as under.

5.2.1 Healthcare functioning factors

Results unveiled that healthcare system functioning constituted elements like funding of the healthcare system and costs related to the provision of public healthcare facilities. It was shown that disruption of functioning deprives the operationalization of the healthcare system,

generating a multitude of problems. These problems arise due to the decreased ability of the governing bodies to invest in the public health facilities. Moreover, the governing bodies, despite being aware of the distinct needs of adolescents, do not have separate facilities for the ALHIV and very few adolescent-friendly services currently exist in Zimbabwe. Due to the decreased funding, the costs of using healthcare services have been increased, along with increase in other HIV treatment related costs. For ALHIV, this increase, translates into decreased access to healthcare, as the financially dependent adolescents amidst of such circumstances are unable to pay for the increased user fee, which directly leads to non-adherence to therapy. Increased user fee played a significant role in decreasing access to treatment facilities in this study, however, in the previous studies, user fees have not emerged as a significant barrier to treatment adherence among ALHIV (185).

5.2.2 Healthcare management factors

Healthcare management aims at the managerial tasks such as ensuring availability of adequate quantity of drugs, medical equipment, and healthcare staff, proportionate to the number of incoming patients. However, the disproportion in the number of patients and staff due to poor management has caused overcrowding of clinics, thus, leading to long clinic waiting times. The results validated that in drug supply, there still lie many problems with the shortage of ARV's and other essential drugs in Zimbabwe. The shortage of drugs in the country stems from the poor planning and management of the supply chain, due to which the resources are not allotted adequately. For ALHIV, when the drugs are in shortage, the adolescents are given lesser than the standard 3 months' supply, meaning, more frequent hospital visits, and more chances of unintentional disclosure, as well as multiplication of treatment costs. In case of unavailability of drugs in the hospitals, patients are asked to buy drugs privately in the local markets. However, the problem with private purchasing is that the local pharmacies sell drugs at a high cost (usually in USD currency, which is very difficult to obtain in the current economic circumstances in Zimbabwe). Another problem is the lack of adequate medical equipment for the staff to treat the patients and the decrease in diagnostic capacity of the health facilities. All of which in one way or the other lead to difficulties for the adolescents in adhering to treatment. Additionally, the aspects of long clinic waiting times and ARV shortages, found in this study, corroborate with previous studies (186), while barriers reported by other studies like missing clinical charts and delays in insurance paperwork, did not arise in this study (113).

5.2.3 Healthcare provider factors

The findings emphasized that the healthcare staff in Zimbabwe is facing dire working conditions, and coupled with the meagre salaries, their motivation for working is extremely low. Results predicted that the underfunding of public hospitals, due to the national level economic collapse, has led to harsh working conditions for the healthcare providers. As the health system is unable to fulfil the financial needs of the staff, it has led to increased attrition rates and brain-drain of Zimbabwe's health professionals. This mass exodus was incited majorly by the inability of the healthcare system to give salaries to the staff, coupled with the lack of essential working equipment and poor work environment. With such poor salaries, the staff are unable to fulfil their domestic needs and the needs of their own families, thereby reducing their motivation and enthusiasm to work. Furthermore, increased attrition of the health professionals also created imbalances in the patient-provider ratio, where the number of patients per health professional is far above the international standard. This imbalance has led to perpetually overcrowded clinics in Zimbabwe, as the people seeking healthcare facilities are steady/increasing, but the providers present to treat them are declining in number. Moreover, as an outcome, the quality of care provided to the adolescents has fallen drastically, since the overcrowded clinics and enhanced workload disables the healthcare staff from investing time to resolve the problems of these adolescents. The findings also suggested that the poor salaries, excessive workload, lack of enough time for ALHIV, and poor working conditions have created a negative attitude in the healthcare providers for the ALHIV. The negative attitude from the health staff towards the ALHIV may be in different forms; i.e. being rude, interrogative, judgemental, shouting and blaming them, due to which the adolescents avoid coming to the clinic to collect their drugs, which directly leads to a reduction in their adherence patterns.

5.3 Individual barriers to treatment adherence

Adolescence is the age of rapid neuronal, physical, emotional and psychological developments. During this phase the adolescents develop their identity, start being recognized by the society and experiment everything. Despondently, the emergence of a life-long, sexually transmitted disease like HIV at such a delicate age, disrupts all aspects of an adolescent's life and the ingrained individual barriers become an important predictor of treatment non-adherence in this age-group discussed as following.

5.3.1 Disease-oriented factors: Anger and bitterness

The negative impact of anger and bitterness was exposed by this study, which predicted that as the parents do not disclose the child's status at the appropriate age, most adolescents are unaware of their reason for taking the medications. Therefore, accidental disclosure leads to feeling of being lied to, which results in the adolescents' anger, bitterness and blaming towards the parents. Moreover, if only one child is HIV positive in a family, it further creates feelings of hatred and bitterness towards all family members, since the child feels different from the other siblings. Results also show that the ALHIV blame their parents from giving them the disease even though it was not their fault. In such situations, non-adherence to treatment is used by the adolescents as a way of resolving their conflicts through self-harm.

5.3.2 Frustration, hopelessness, demotivation factors

Results depict that in Zimbabwe, no particular future opportunities exist for ALHIV. Most of them do not go to school due to stigma or lack of money, whereas, others do not have a source of earning, therefore, for these adolescents, living such a life is a burden. Moreover, the heightened feeling of assimilation arises during adolescence, but the emergence of HIV leads to restrictions in their sexual life and choices as well. Therefore, these adolescents do not find drug taking to be beneficial for them and being frustrated with life, also try to commit suicide.

5.4 Medication barriers to treatment adherence

The hindrances encountered by ALHIV in adhering to treatment, owing to medications comprise the medication barriers. The Food and Drug Administration (FDA) defines medication as: a drug employed to treat, cure, prevent or diagnose a disease (187). The lifelong treatment of HIV, expected to be taken diligently every day, and the need to adhere to treatment despite the unpalatability and side effects of drugs is challenging for these adolescents. Medication barriers entail adherence problems related to two factors i.e. treatment regimen factors and pill factors, both of which are debated below.

5.4.1 Treatment regimen factors

The results reveal that due to the life-long commitment of ART and the treatment regimen, ALHIV feel fatigued, as they have no motivation and taking pills is only seen as a burden and public marker of being positive; a major reason why adolescents do not adhere to their treatment. The stress of abiding by a strict medication schedule and remembering to take pills every day, throughout one's life is daunting for adolescents, particularly because they have to take their medications regardless of their daily schedule (which for most adolescents is difficult

to accomplish, as the adolescents are more social, living in boarding schools or with foster families), therefore, they suffer from treatment fatigue.

5.4.2 Pill factors

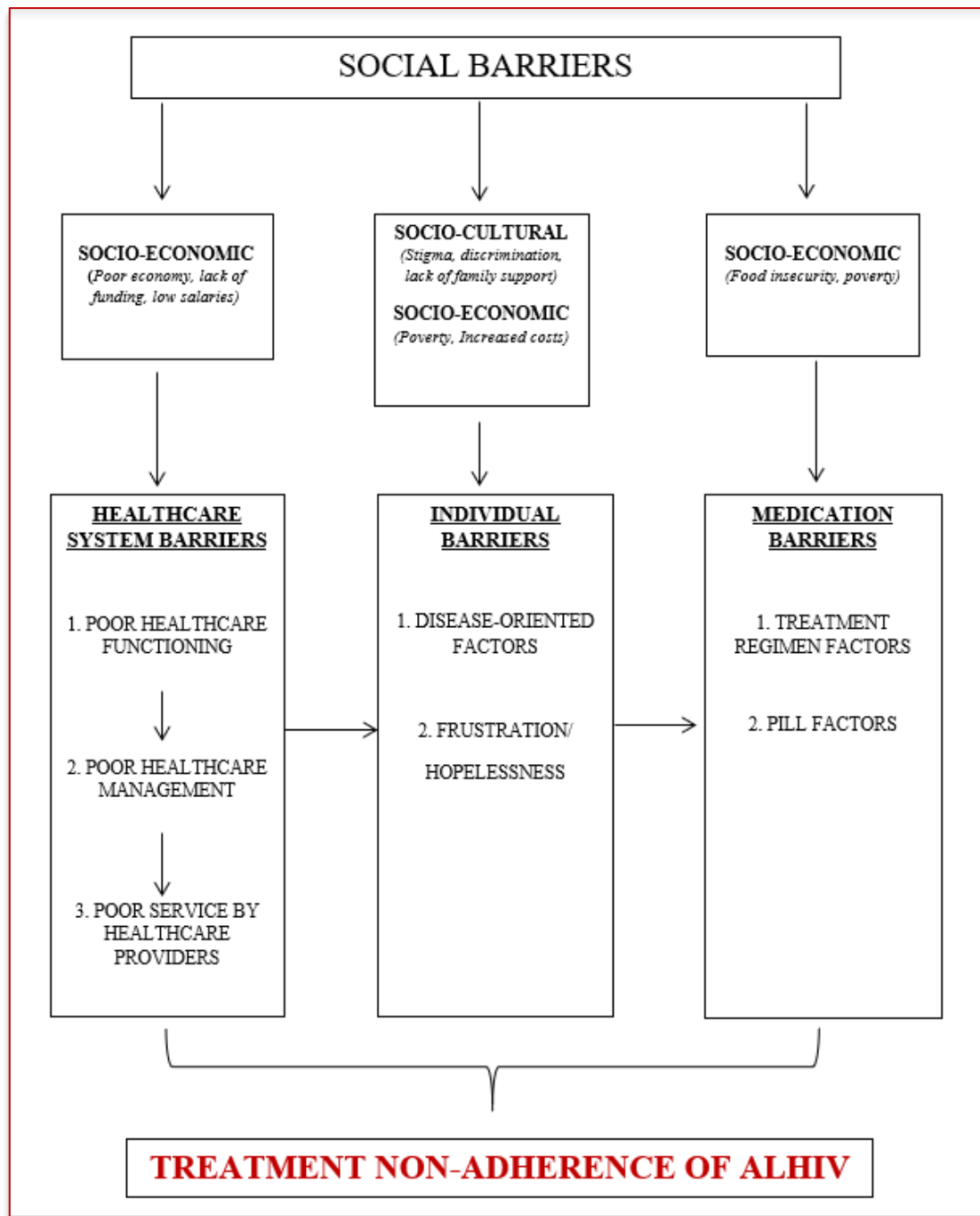
In addition, the findings suggested that characteristics of the pills themselves also serve as barriers in adhering to treatment for ALHIV. The barriers related to pill size, pill number and taste arise due to being motivated to take the medications and also because of the absence of any supportive entity during the difficult phases of their illness. Moreover, they have difficulties in swallowing and ingesting drugs, and due to the large size, taste and bad smell, the adolescents refrain from drugs. On a broadscale, the unavailability of child-friendly dosage-forms results in children's refusal to take medicines. The ALHIV are further de-motivated to take the medications when they suffer from any side-effects, as suggested by results. Now, Fixed-dose combinations (FDCs) and Once daily dosing (ODD), which produce lesser side effects are prescribed preferably. Yet, adolescents still complain of feeling dizzy, sleepy or insomniac with usage of drugs, additionally, nausea and vomiting has also been reported, therefore, side effects present a major barrier in adolescents' aversion from treatment. Although the adolescents are given complete information about the drugs, their adherence and the possible adverse effects, yet they do not adhere well to their treatment and have an erratic drug taking, which leads to negative consequences in the longer-run.

The four themes and their corresponding barriers discussed above indicate and explain the barriers to treatment adherence among ALHIV in Zimbabwe. Upon analysis of these barriers, this study also found that along with the individual existence and negative impact of these barriers on treatment adherence of ALHIV, they are also correlated and thus, interconnectedly, aggravate the treatment adherence of ALHIV, discussed in the next section.

5.5 Inter and Intra-relationship among barriers of treatment adherence

Data analysis and interpretation of results showed that, in addition to the generation of treatment non-adherence by the above-mentioned barriers individually, there also lies an inter and intra-relationship amongst them, where one barrier incites the other barriers, which results in treatment non-adherence. Presented below is the relation and process, depicting that social barrier induces and becomes the reason for the creation of the subsequent barriers (see Figure 4).

Figure 4: Inter and Intra-relationship among treatment adherence barriers



Social barrier emerged as the overarching barrier, responsible for the formation of socio-cultural and socio-economic factors, through which the healthcare system, individual and medication barriers are propelled. In the social barriers, the socio-economic factors firstly impact the healthcare system through the poor national economy and decreased healthcare funding, leading to poor functioning of the healthcare system. As a result of the poor healthcare functioning, the management of the healthcare system also becomes futile, due to which, the

healthcare staff suffers, deteriorating and worsening their performance. Owing to the unsatisfactory and negative attitude of the healthcare staff, the individual barriers such as anger, bitterness, frustration, demotivation, hopelessness and suicidal thoughts are ignited in the adolescents, owing to the lack of support from the healthcare staff and the absence of future prospects. Simultaneously, the socio-cultural (stigma, disclosure, lack of family support) and socio-economic factors (poverty, increased costs) together lead to the generation of these individual barriers, that further result into treatment non-adherence. Subsequently, the individual barriers, concurrently with barriers from the social aspect (socioeconomic factors; food insecurity), stimulate the formation of medication barriers, portrayed through treatment fatigue and others like, pill size and number as well as the side effects of drugs, all leading to treatment non-adherence among ALHIV.

The above-mentioned model, representing the inter and intra-relationship among the barriers, depicts the way in which each barrier incites and stimulates the formation of the subsequent barrier. Moreover, this model will facilitate in identification of the obstacles around ALHIV, that generate treatment non-adherence, in addition, it will also assist in proposing effective strategies that improve adherence to treatment for ALHIV.

5.6 Strategies to improve treatment adherence among ALHIV

The previous sections have focussed on the detailed elucidation of the reasons for adolescents' non-adherence to HIV treatment, while underscoring the relationship among the barriers. In accordance with the aim of this research, this section will propose effective strategies intended for policy makers and all stakeholders involved in the ALHIV treatment cascade, to mitigate the barriers to treatment adherence.

An overview of the barriers to treatment adherence depicts that these barriers are spread over multifarious systems surrounding an adolescent, which justifies a joint collaboration of all systems involved in the HIV treatment of adolescents. ALHIV form a distinct group of people, therefore, the interventions directed at this population must be tailored to their specific needs. The designing and implementation of such interventions will not only enable increase in adherence but will also lead to the actualization of the UNAIDS 90-90-90 targets in low-income countries like Zimbabwe. Proposed following are the strategies pertaining to the four treatment adherence barriers uncovered through this research in descending order of their significance.

5.6.1 Strategies to Improve Social Barriers to Treatment Adherence

Society forms a major part of an individual's life. In the context of this research, the major social barriers discovered are related to faith healing, stigma, discrimination, disclosure, family environment and financial issues. In view of these social barriers, the following interventions are proposed.

5.6.1.1 Collaborating with faith healers

As the social issue of faith and traditional healing is highly prevalent in Zimbabwe, and bears a strong social influence, this study suggests that the faith healers must be taken aboard in order to improve adolescents' adherence to treatment. Alliance and collaboration with religious institutions and faith healers must be established in order to avert adolescents' non-adherence to treatment through faith healing. Previous studies have verified that taking faith healers on board is an effective way to improve adherence (188).

5.6.1.2 Counteracting stigma and discrimination: Promoting onward disclosure

Results revealed that stigma and discrimination regarding HIV is deeply rooted in the Zimbabwean society, therefore, disclosing the child's HIV status is crucial in their treatment adherence. Proper disclosure skills must be taught to the families of such adolescents, which will not only enhance their psychosocial support, but also, sustain and improve adherence. Moreover, disclosure amongst the family, partners, peers and society is a grave concern for ALHIV. Therefore, as suggested by the respondents, onward disclosure must also be encouraged among adolescents. Disclosure can be achieved through empowering adolescents, leading to an increased social acceptability of PLWHIV, as also suggested by earlier studies (189).

5.6.1.3 Enhancing family support

Family plays a vital role in an adolescent's life as discovered, particularly during the challenging time of living with HIV. Family support not only increases adherence to treatment for adolescents, but also increases support around the ALHIV. Additionally, involving family in the responsibility of the ALHIV's treatment will also increase ART adherence. The positive role of family's involvement is also confirmed by other studies (190).

5.6.1.4 Economic empowerment

In the prevalent poor economic situation of Zimbabwe discovered through results, financial dependency of ALHIV is a major barrier to treatment adherence. Therefore, economic

incentives must be used for ALHIV to empower the adolescents economically or food rations can be given to improve adherence to treatment. As the results depict, the lack of future opportunities for ALHIV in Zimbabwe, another way of empowering adolescents in low income countries could be to provide work opportunities to enable financial stability and remove adherence issues arising due to financial restraints. Economic incentives have been used by some studies in adults, which could also be employed in adolescents (191).

5.6.2 Strategies to Improve Healthcare System Barriers to Treatment Adherence

The healthcare system of Zimbabwe is in limbo due to a myriad of financial, political and structural deficiencies. These comprise of issues related to the healthcare functioning, management and staff. The strategies proposed below aim to curtail these factors which can improve treatment adherence of ALHIV both directly and indirectly.

5.6.2.1 Removal of user fee

In view of the study results, user fee decreases access to healthcare facilities and is a major barrier to adolescent's non-adherence to HIV treatment. Majority of the ALHIV belong to disadvantaged families, therefore, user fee must be removed from all HIV-related services, to increase access of ALHIV to the healthcare facilities.

5.6.2.2 Managing drug shortages

Drug shortages are a major problem in Zimbabwe, as emerged through results, however, in order to eradicate this problem, the funding of the healthcare system must be increased. Loopholes in the supply chain system must be examined to prevent future shortages. Nonetheless, to ensure un-restricted availability of drugs, strategies such as borrowing drugs from other facilities, substitution of the ARV's in short supply and referring patients to larger facilities with copious drug supply should be implemented. This has also been suggested by other studies (192, 193).

5.6.2.3 Improving working conditions for the healthcare staff

Poor working conditions for the healthcare providers appeared as a barrier to delivery of quality care to the ALHIV. Therefore, it is necessary that the providers must be strengthened and motivated to give the best care. This can be accomplished in various ways, via provision of a good working environment. In addition, delivery of timely, fair-pay, financial and non-financial incentives must be ensured, as well as encouraging the retention and return of healthcare providers.

5.6.2.4 Training of healthcare staff to deal with ALHIV

As results show, ALHIV represent a diverse group of individuals and caring for them necessitates specialized skills that require considerable time, patience and effort. Therefore, the healthcare staff must be trained to show empathy towards these adolescents and fulfil their specific needs, so that they may be facilitated in adhering well to their ART treatment. Usage of friendly, non-judgemental and positive attitude must be encouraged. Training the healthcare providers to improve adherence has also been stated by earlier studies (194).

5.6.3 Strategies to Improve Individual Barriers to Treatment Adherence

The individual barriers of anger, bitterness, lack of motivation and frustration are provoked in the adolescents as a result of the lack of support and care from the society. Therefore, strategies to overcome these individual barriers must focus on establishing support networks around these adolescents and empowering them through various means.

5.6.3.1 Support drug taking

As results show that adolescents lack the support in taking medications, supporting them to take treatment each day is necessary for un-interrupted drug taking. This could be achieved using reminders, and text messages could be used to increase adherence to treatment which may also habituate them towards regular medication taking. The use of behavioural interventions as reminders for drug taking is confirmed by previous studies (112).

5.6.3.2 Differentiated service delivery and care

As ALHIV represent a distinct group of PLWHIV, their HIV care requires separate services from adults and children, tailored to their needs. Such interventions could include the formation of adolescent-clinics at every health facility, to maximally ensure their care and enhance their involvement in treatment. In addition, adolescent-friendly services and flexible clinic hours, places for education, care, treatment and entertainment for ALHIV should be introduced. These strategies will not only improve future prospects for ALHIV and increase their motivation towards life but will also increase their adherence to treatment.

5.6.4 Strategies to Improve Medication Barriers to Treatment Adherence

The primary adherence barriers related to medication resulted from treatment fatigue, pill burden and side effects of medications. As results show that most ALHIV find medication taking embarrassing, strategies that ease their treatment must be implemented.

5.6.4.1 Long-acting ART, Short-Cycle Therapy (SCT) and Transdermal patches

Exhaustion from taking treatment and many pills for a lifetime causes treatment fatigue and pill burden among the ALHIV. The advancements in medical science and technology must also be used for eradication of barriers to adolescents' treatment and use of drugs with long-life must be investigated. This may reduce the number of pills and the need to take medications each day and may also reduce side effects. Furthermore, other strategies like ART-free weekends, to allow for planned breaks between treatment must be used in order to overcome barrier of treatment fatigue. As results also show, that public taking of medicines is associated with stigma and accidental disclosure of status. To overcome the barriers of stigma attached to taking medication publicly, transdermal patches or ART similar to nicotine patches could be used that will protect the privacy and overcome adolescents' fears of unintentional disclosure, thereby improving adherence to treatment. Earlier studies have also suggested the usage and exploration into the possible options of longer acting drugs and transdermal patches, so as to mitigate the adolescents' barriers to treatment adherence (195).

Concludingly, the strategies stated above have been proposed through pinpointing the barriers that lead to treatment non-adherence among ALHIV, therefore, they target the areas in the HIV treatment of adolescents that still need improvement. Nonetheless, as uncovered through the inter and intra-relationship model among the barriers of treatment adherence, social barriers emerged as the most prominent hurdles in hindering adherence to treatment for ALHIV. Therefore, prioritized efforts should focus to resolve these, so that they do not lead to the subsequent problems (as discovered through the development process). Although challenging, the implementation of these strategies requires consistent effort and help from all stakeholders in the HIV care continuum. These strategies serve as a guiding light for improvement of treatment adherence, so that the WHO targets of ending AIDS epidemic by 2030 may be successfully achieved.

Chapter 6: Conclusion, Limitations and Future Research

6.1 Conclusion

This study unveiled the barriers to treatment adherence for ALHIV and proposed effective strategies to improve the treatment adherence of ALHIV in Zimbabwe, in accordance with the 2017 research priorities set by the IAS and WHO (68). The results of this study revealed four barriers to treatment adherence i.e. Social, Healthcare system, Individual and Medication barriers, associated with the different systems and interactions surrounding the ALHIV. The social barriers overarch the other barriers and serve as the causative agent for generation of healthcare system, individual and medication barriers, through its multi-layered socio-cultural and socio-economic factors. Therefore, through the inter and intra-relationship model of treatment non-adherence among ALHIV, the results of this study underscore that along with the medical interventions for improving treatment adherence, the social barriers must also be taken into consideration while designing the adherence interventions. The healthcare system must improve its financing, so that the functioning and management of the healthcare system can be run properly. This improvement of healthcare system management and functioning will improve working conditions and enhance the motivation of healthcare providers to deliver best quality of care to ALHIV. Moreover, for the individual adolescent, future opportunities and support must be increased, so that they envision an optimistic future. Lastly, the development of age-specific and long-acting medications for the ALHIV must be incentivized to increase medication adherence, which will facilitate achievement of UNAIDS target of ending AIDS epidemic by 2030. The results of this study have helped formulate interventions specifically targeting ALHIV, in the resource-limited settings of Zimbabwe. Although, a broad perspective of barriers to treatment adherence was attained through viewpoints of healthcare providers functioning in various capacities (counsellors, nurses, medical doctors), this research was not devoid of limitations:-

6.2 Limitations

Since this research was conducted at the master's level; therefore, it had a pre-determined timeframe and the data analysis could not be done in more detail. Owing to the limited timeframe, this study focussed only on the capital city; Harare, describing the views of healthcare providers working only in this urban setting. Next, although gathering information from the healthcare providers diversified the scope of this research and richness of the data gathered, the respondents may have underestimated the factors related to healthcare providers that served as

barriers to treatment adherence of ALHIV. Lastly, only the primary researcher conducted all steps of data analysis from transcription, coding till generation of themes. It is assumed that the researcher's preconceptions might have biased the study results. Nonetheless, the researcher in consultation with the supervisors, thoroughly reviewed all stages of data analysis, coding and formation of themes, through an iterative process to lessen the effect of researcher bias on study results.

6.3 Future Research

The results of this study highlight the entry-points for generation of the inter and intra-related barriers to treatment non-adherence of ALHIV, which should be utilized to establish focussed and targeted interventions in the future. As this study had a limited timeframe, future studies may investigate the barriers to treatment adherence and the changes in barriers over time throughout Zimbabwe, using a longitudinal study design. Although, the present study gathered the views of both male and female healthcare providers, it did not assess the difference in their views, which may possibly differ. Therefore, future studies should take into account, the differences between the views of both male and female healthcare providers. Furthermore, the views from three types of healthcare providers, i.e. counsellors, nurses and doctors were included in this study. However, the counsellors managing ALHIV, spend the most time listening and solving their life and treatment adherence challenges, so, their views must be studied in the future and a comparison amongst views of these three health providers be assessed. Additionally, as the present research was conducted in a low-income country with deeply rooted cultural norms and values, future studies may examine such barriers in high income countries to observe any deviations in cultural and economic barriers of the high-income countries. Moreover, the effect of treatment non-adherence among ALHIV and its impact on the families and caregivers of these adolescents; the first-hand receptors of this impact should also be studied. Lastly, the difference in barriers among the perinatally and behaviourally infected ALHIV must also be examined in the future.

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Appendices

Appendix I: Demographics of Research Participants

Table 2: Demographics of Research Participants

<i>Sr. No</i>	<i>Participant Demographics</i>		
<i>1.</i>	<i>Age</i>	25-57 yrs.	
<i>2.</i>	<i>Gender</i>	Male	8
		Female	10
<i>3.</i>	<i>Origin</i>	Zimbabwean	16
		Non-Zimbabwean (UK)	2
<i>4.</i>	<i>Profession</i>	Counsellors	9
		Nurses	6
		Medical Doctors	3
<i>5.</i>	<i>Experience in working with ALHIV</i>	6-18 yrs.	
<i>6.</i>	<i>Total number of participants</i>	18	

Appendix II: Interview Guide

Aim and Objective

This research aims “*To identify the barriers to treatment adherence among ALHIV in Zimbabwe and to develop effective strategies to increase their adherence to treatment*” from the perspective of Healthcare providers in Zimbabwe, who work intimately with such individuals. To achieve this aim, the following research objectives will be used: Data will be collected from health care providers, detailing the reasons behind treatment non-adherence among ALHIV in Zimbabwe. To critically assess and evaluate the most prominent reasons of treatment non-adherence among ALHIV. To make recommendations for proposing effective strategies to improve the treatment adherence among ALHIV.

Research Questions

The study at hand is a two-fold study, wherein with regard the to the research problem, this study entails the following research questions:

1. What are the barriers to treatment adherence for ALHIV in Zimbabwe from the viewpoint of the healthcare providers?
2. What can be the most effective strategies to improve adherence to treatment for ALHIV?

In order to fulfil the objectives of this research, face-to-face interviews will be carried out with the healthcare providers working with ALHIV, in a place where they can express their views openly without any hesitation. For carrying out the interviews, a semi-structured interview guide will serve to direct the flow of the interview.

Introductory questions:

- Name, age, gender
- Origin
- Experience with ALHIV

The interview guide will be divided into 4 themes, where each theme will comprise of probes, that will be used to elaborate and broaden the topic of discussion and gain an in-depth understanding of the topic.

1. HIV in Zimbabwe

- 1.1. Pandemic trends
- 1.2. Severity of HIV
- 1.3. Death rate
- 1.4. History of pandemic
- 1.5. Transmission of HIV
- 1.6. Precautions against HIV

- 1.7. Services for affectees
- 1.8. Region wise Affectees
- 1.9. Demographics of affectees

2. Adolescents living with HIV

- 2.1. Defining adolescents
- 2.2. Statistics of adolescents in Zimbabwe
- 2.3. Reason of virus in adolescents
- 2.4. Poverty in adolescents
- 2.5. Education level
- 2.6. Services for adolescents
- 2.7. Treatments for adolescents
- 2.8. Lifestyle of adolescents
- 2.9. Relationships
- 2.10. Psychological state of ALHIV

3. Treatment adherence

- 3.1. Defining
- 3.2. Medications for HIV
- 3.3. Treatment process
- 3.4. Treatment adherence stats
- 3.5. Treatment adherence barriers
- 3.6. Reasons behind treatment adherence
- 3.7. Severe most barriers
- 3.8. Barriers related to healthcare staff
- 3.9. Relationship of healthcare staff with ALHIV
- 3.10. Role of healthcare provider in treatment non-adherence

3.11. Socio cultural and Socio-economic barriers

3.12. Treatment regimen

3.13. Medical drugs

3.14. Treatment expenses

4. Strategies for improving treatment adherence

4.1. Barriers to non-adherence

4.2. Mitigation of barriers

4.3. Policies for barriers

4.4. Practical strategies for adherence

Appendix III: Participant Information Sheet

Participant Information Sheet

Department of Public Health and Nursing

Barriers to Treatment Adherence among ALHIV and Strategies to mitigate them: A Viewpoint of Healthcare providers in Zimbabwe

Introduction

Welcome and thank you for volunteering to take part in this research, I am Sarah Mariam, a postgraduate student of Global Health from Pakistan, currently studying at Norwegian University of Sciences and Technology NTNU, Trondheim.

What is the purpose of this research?

In spite of the successful implementation and subsequent decrease in mortality of people from all age groups in Zimbabwe, the prevalence in adolescents living with HIV is increasing and has not observed a steady decline unlike other age groups. Adherence to retroviral therapy is crucial to controlling the disease, as ART can suppress viral replication for years, resulting in near normal life. ART non-adherence is a major hurdle in the successful effectiveness of ART among adolescents living with HIV, due to their physical, psychological and mental developmental stages, adolescents are faced with peculiar adherence problems. Studying adolescents' adherence to ART is essential and a research priority pointed out by the WHO in its 2017 global research agenda. Adherence to ART is effected by many barriers and the role of healthcare providers is pivotal in adherence to ALHIV treatment as they remain in close association with the affected individual. Therefore, research has suggested that the perspectives of health care providers be studied in relation to barriers to adolescents' treatment adherence.

Through purposive sampling of healthcare providers (doctors, nurses and counsellors) will be interviewed. The aim of this study is to understand the barriers to treatment non-adherence of ALHIV and propose effective strategies to improve adherence among ALHIV from the view of health providers, who have a significant role in the treatment of ALHIV.

The findings of this study will prove beneficial for the society as adherence to ART is a major challenge for ALHIV, particularly in Africa. Healthcare providers play an eminent role in treatment completion; therefore, the results of this study shall assist in highlighting the barriers to treatment adherence in ALHIV from the perspective of healthcare providers and will elucidate the recommendations made by them to improve adherence.

Do you have to take part?

Participation in this research is voluntary meaning that you can choose not to take part in this research. I would also like to bring it to your knowledge that signing this consent form does not bound you to answer every question. Please do not to share anything more than you are comfortable with during our interview/discussion. If there are any questions that you do not wish to answer, you do not have to do so and you can finish the interview/discussion as well as leave the research at any time if you would like to, without having to present any reasons.

What will you do in the project?

Your views and perspectives on the topic at hand will be inquired through open-ended questions using semi-structured, face-to-face in-depth interviews and or focus group discussion lasting for about 60-120 minutes, conducted at the designated site.

Why have you been invited to take part?

You have been asked to participate in this study as your point of view is relevant and necessary for my study. I am aware of your busy schedule and appreciate the time you have spared for this interview/discussion. I do not expect that participating in this study will cause you any harm. I will learn by hearing your opinions and including them in my study will be beneficial for others in the future.

What information is being collected in the project?

Through these in-depth interviews and focus group discussions, your viewpoints on the role of health care professionals on improving treatment adherence among adolescents living with HIV will be obtained. The information will be pseudo-anonymous, meaning that I will not use any information that will identify you, thus your confidentiality will be maintained throughout and after the research.

Who will have access to the information?

No one except me or my supervisors will have access to this information. With your permission, I will tape this discussion to facilitate recollection. Despite being taped, I would like to assure you that the discussion will be anonymous. The tape will be kept safely in a locked facility until it is transcribed word for word, then it will be destroyed. The transcribed notes from the interview/focus group will contain no information that would allow individual subjects to be linked to specific statements.

Where will the information be stored and how long will it be kept for?

The information collected from these interviews will be stored on a password protected USB device for a period lasting no more than one year after which the data will be destroyed. During the period of data storage, they will be kept in a safe place to avoid the leakage of data.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

If you have questions or would like to find out more about the project, you can contact my supervisors and me; for which the contact information is below:

1: Jon Oyvind Odland
Professor in Global Health, MD, PhD
Norwegian University of Science and
Technology Trondheim, Norway
Telephone +47-90953887
Email: jon.o.odland@ntnu.no

2: Dr. Grace McHugh
Breathe Trial Coordinator and Trial Physician
MB BCh BAO MD
Biomedical Research and Training Institute, Harare, Zimbabwe
Telephone: +263-773957611

Email: graceandandre@gmail.com

Primary researcher contact details

Sarah Mariam

Student of M.Sc. Public Health (Specializing in Global Health)

Norwegian University of Science and Technology,

Trondheim, Norway

Telephone +47-93989226

Email: sarma@stud.ntnu.no

Appendix IV: Consent Form

CONSENT FORM

Department of Public Health and Nursing

Barriers to Treatment Adherence among ALHIV and Strategies to mitigate them: A Viewpoint of Healthcare providers in Zimbabwe

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that I can request the withdrawal from the study of some personal information and that whenever possible researchers will comply with my request. This includes the following personal data:
 - audio recordings of interviews that identify me
 - my personal information from transcripts
- I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to be a participant in the project.
- I consent to being audio recorded as part of the project

Name/Code:	
Signature of Participant:	Date:

Appendix V: Steps of Thematic Analysis

Table 3: Steps of Thematic Analysis

Sr. No	PHASES	PROCESS DESCRIPTION	IMPLEMENTATION IN RESEARCH
1.	Familiarization with Data	Transcribing and re-reading data, writing preliminary ideas	First step comprised of being immersed in the data by repetitive listening to the interview audio recordings and reading of the interview transcripts, during which initial codes/points of interest related to the research question were highlighted. This enabled the primary researcher to be thoroughly acquainted with the entire data.
2.	Generating Initial Codes	Coding relevant data features throughout the transcript, collating data into codes	The entire transcripts were read several times and anything relevant to the research question was highlighted, which was then collated together and identified by codes.
3.	Searching for themes	Checking patterns in Codes generated in previous step and coming up with themes	Similar codes were grouped into themes and sub-themes to formulate coherent and meaningful patterns in data. Irrelevant codes were discarded,
4.	Reviewing themes	Specifying each themes and relating to codes and data set, forming thematic map	Themes developed were analysed in relation to the coded data as well as the whole data set, achieved through another final reading of the whole data. Any missing points were added, and modifications made to ensure the representativeness of the themes to the data. This phase ended with a thematic map/table of analysis
5.	Defining and naming themes	Refine themes and overall story of the analysis, generating distinct theme names and definitions	After finalizing the list of themes, they were named according to the theme's central focus, using succinct and easily comprehensible names.
6.	Producing the report	Selecting compelling examples of extracts, relating analysis to research question and literature, producing report	As characteristic of qualitative research, writing and analysis happen concurrently, nonetheless, it involves addressing each theme and its contents, its relation to the previous themes and their meaning, employing data as evidence for it.

Appendix VI: Trustworthiness in the Study

Table 4: Trustworthiness in the Study

Sr. no	CRITERIA	DEFINITION	IMPLEMENTATION IN RESEARCH
1.	Credibility and Confirmability	To assure that appropriate data collection method was used, and the quality of the data collected was pertinent , additionally, the experience of research participants was suitable for the research	<p>In view of the research question, pre-set criteria based on participant experience was used for choosing participants. The participant selected were healthcare professionals i.e. doctors, nurses and counsellors that had experience of at least 5 years in dealing with the ALHIV. These healthcare professionals dealt with the ALHIV closely in various capacities and were thus able to provide rich descriptive information related to the treatment adherence barriers</p> <p>Peer debriefing was utilized to assess the objective formation of codes, categories and themes emerging from transcripts. Data was transcribed verbatim completely and correctly, and raw data was used to derive quotations used in the results.</p>
2.	Transferability	The extent to which study results can be transferred to other individuals, groups and study findings be employed in other studies as well	<p>This study has been described in detail so as to be able to be replicated, through elucidation and definition of descriptions from the perspective of respondent viewpoints .</p> <p>The researcher has ensured to provide a detailed description of the setting of the study, the participants, observations and the methodology employed in data collection and analysis, and its reporting for facilitation of usage by other researchers in similar settings.</p>
3.	Dependability	Assessing data quality through measurement of consistency and explicit description of study process and report	Conscientious record and documentation of all interview data ad transcripts was kept so as to track the data and in similar setting, allow for research replication.

Appendix VII: Ethical Approval



BIOMEDICAL RESEARCH AND TRAINING INSTITUTE

A Non-Profit Organization Promoting Health
Research for Development in Southern Africa

10 Seagrave Road
Cur S. Nujoma St & Seagrave Rd
Avondale
Harare
P.O. Box CY 1753
Causeway, Harare, Zimbabwe
Tel: 263 4 336691; 335641; 333091
Fax: 263 4 333464
E-Mail: rpilze@brti.co.zw
Website: <http://www.brti.co.zw>

Faculty of Health Sciences
NTNU

Høgskoleringen 1, 7491 Trondheim,

Norway

28/10/2019

Dear Sir/Madam

This letter serves to confirm that qualitative research interview being undertaken by Ms Sarah Mariam, Masters student, while on attachment at Biomedical Research and Training Institute, Harare, Zimbabwe will be done under ethical approvals of the BREATHE clinical trial. Her interviewing of BREATHE clinical staff will serve to help understand the role of health care providers in assisting adolescents adherence to antiretroviral therapy. The planned study will be from September 2019 ending May/June 2020.

Yours sincerely

Dr. Grace McHugh MB MRCPI MD

Breathe Clinical Trial Coordinator gmchugh@brti.co.zw

Directors: T. Rwodzi (Chairman), P.R. Mason, S. Muziyati, C.J. Shiff, S. Guramatinhu, L. Zizema, A. Ndima, L. Gwasanzura, C. Samkanga, S.A. Gregson, E. Gomo

Appendix VIII: Themes, Categories and Corresponding codes

Table 5: Themes, Categories and Corresponding codes

Sr. No	Theme	Category	Code	Quotations
1.	SOCIAL BARRIERS TO TREATMENT ADHERENCE	Socio-cultural factors	Religion/Faith healers	<p>... “we have a proliferation of faith healers uhh those are giving off problems and you know adolescents normally they want to find escape route, route someone said I’ve prayed for you no longer have the virus then they would be happy yes, I’m healed I’m not free from taking drugs”</p> <p>.... “some they say uhh I was told to stop the medication from the church, some they say we went to see the Sangoma’s and they give us the concoction and I’m now HIV negative” ...</p>
			Traditional healers	<p>.... “someone was telling me last year, I tested him, and he was HIV +ve, but then he said no, in my tribe no one gets sick with HIV, it has never happened so you and your devices that detected that I’m HIV +ve are all wrong my tribe doesn’t acquire HIV”</p> <p>... “some kids yeah, and their parents’ beliefs are very important, this whole issue if which doctors and people stopping drugs go and see alternative medicine alternative care, it usually happens because there’s someone senior to them influencing them to do that” ...</p>
			Social-Ban	<p>...” people still have that strong strong strong stigmatization of the disease. So, it’s one of the biggest biggest challenges where stigmatization would really lead to uhh non-adherence and people would default all those things affect how young people take their drug” ...</p> <p>... “Stigma because they feel they will be stigmatized, and they feel their partner will say um umm I don’t want somebody who’s infected” ...</p> <p>...”it is not as attractive to go to your local clinic because you worry that maybe people will talk about you outside of the clinic”</p> <p>...” Disclosure takes many forms uhh the need to disclose to makes problems disclosing to their, to other family members, friends, teachers, sometimes they just worry themselves I ask some adolescents they talk about stigma and discrimination”</p>
			Socio-familial issues	<p>.... “they don’t have family support, they live with relatives who don’t like them, who stigmatize them who actually don’t support them so at the end of the day they probably decide to say so why should I take the drugs” ...</p> <p>...” Their drug taking can be dependent on the adult person who may not be supportive, the adherence aspect also relate to, the family support” ...</p>

				<p><i>they have to rely on their adult person to give them bus fare, so that they can go to the clinic, they have to rely on the adult person to give them food, so that they can take their drugs” ...</i></p> <p><i>... “there’s no food no school fees, So that demotivates them, why should I continue to take the tablets” ...</i></p>
		Socio- Economic factors	Recession/inflation/ Poverty/unemployment	<i>... “We’re going through a period of hyperinflation” ...</i>
			Food insecurity	<i>They would tell you, I didn’t have food, so I couldn’t take my drug</i>
2.	HEALTHCARE SYSTEM BARRIERS TO TREATMENT ADHERENCE	Healthcare functioning factors	Decreased healthcare funding	<i>... “there is very less healthcare funding in the health system, for hospitals, doctors and drugs”.</i>
			Increased user fee + transport fare	<p><i>..”Umm I think user fees are a barrier definitely and these have recently been increased as well”..</i></p> <p><i>... ” people living with HIV who attend primary are clinics do have to pay for a user fee to access the service which in harsh economic times could act as a barrier to care” ...</i></p> <p><i>...” the user fee because I know it’s one of the deterring factors”.</i></p> <p><i>..”issues like the bus fare issues like bus fare because transport fare have already gone up”..</i></p>
			Staff shortage	<i>..”over the past few years and I think it’s the issue of economic hardships in Zimbabwe and even the hospitals and the city health, their employment I think has gone down</i>
			Low staff salaries	<i>.... “there is a problem salaries we ve always really big clog, about 3-4 months, the salary is next to nothing”..</i>
			Imbalanced patient-provider ratio	<i>... “The workload it’s too much! As compared because if you see the patient to provider ratio is very high” ...</i>
		Healthcare management factors	Unavailability of drugs/expired drugs	<p><i>.... “we still have so issues of drug shortages” ...</i></p> <p><i>.... ”they have shortages, at the ministry but what they do when they have shortages they’re not because now they can give up to 3months supply but when they are shortages, they will give maybe two-week supply”..</i></p>

				<p>.. "at times you find that umm some of the ART drugs are not available" ...</p> <p>.. "Some time back availability of medication was okay but now it is becoming a problem sometimes you don't find the medication that you want in the clinic, so you'd have to write you a prescription then you go and buy it maybe in the pharmacies" ...</p>
			Decreased Diagnostic capacity "We need to strengthen our diagnostic capacities and our access to viral load testing" ...
			No Medical equipment "There's need for more equipment" ...
		Healthcare provider factors	Poor working conditions	... "the issue comes again umm our providers, uh let's talk about maybe the nurses who are working with the counsellors who are also working with uh the patients, how many are they? And how many patients are they seeing? It's overwhelming, is it a clinic, and we I was there in the clinics for some time, we could have umm few clients that I would be seeing a day but I will be seeing them on my own but we look at one nurse with so many benches and now you say how is that nurse going to give time to each of them? They look at time, they need to clear the bench and now they are saying are they Ummmm for us to have uhh to have health facilities that are going to be able to give good quality umm service there's an issue of looking at uhh how many clients or how many patients is this nurse distribution of uhh of uhh patients to one provider because it is overwhelming, that's why there is an issue of ban-out, that's what I see in our health facilities, there is an issue of ban-out. Because the health providers are not good, they are overwhelmed" ...
			Excessive workload	.. "its unequal(the workload), it's just too much, you can tell that the nurse is just overwhelmed, you have to move from one point to another and right now maybe because of the economic situation in Zimbabwe, it's because they have to come to work maybe 3 times a week. It means those that are on duty they have to work from 7am to 7pm, that's not healthy and we expect them to give good quality service to our patients who are coming and they are not well, they are sick and need help, it might be psychological, it might be social, it might not be the headache they say, but it might be a headache because of social issues. They come to the clinic they just, you won't even have time to listen, their benches are full, you need to clear them in a full, you know all the clients. So, its ratio is not good not because our clinics are not good, but they are good but i think it's the issue of ratio and people, the providers end up not doing the quality that we think they should do, so they are pushed. At times they are over-whelmed, the ban-out you know with ban-out you can't do anything yeah. I think.. I think it's been going on

				<p><i>for many years now and before it.. I think the ratio was much better yes but for now I think it's issue, ratio is just getting worse and worse”..</i></p>
			No time for ALHIV	<p><i>... “It’s unfortunate that our average time usually is 10 minutes that’s the maximum”..</i></p>
			Frustration of staff	<p><i>.. “when we want to collect a specimen for viral load and there are no gloves or there’s no needle or there’s no tube or there’s no syringe. It’s already frustrating on its own”..</i></p>
			Negative attitude towards ALHIV	<p><i>... “one of the reasons why they don’t go to the clinic is because of the attitude of the nurse</i></p> <p><i>And it’s mostly about the healthcare professional making them feel bad about themselves, yeah. That example of they’ll be cross with me If I tell them I haven’t taken the tablets, So yes, their perceptions are that they’ll be punished or they’ll be shouted at, but I was too scared to come on Wednesday because sometimes I come and I get told you missed your appointment you have to come back next week. So, that sort of, some the healthcare worker put on barriers to try and punish the kids which is.. shocking</i></p> <p><i>The attitude of the provider is a barrier, yeah to adherence, today if I come, maybe I skipped one, and I’m told, you know started shouting</i></p>
3.	INDIVIDUAL BARRIERS TO TREATMENT ADHERENCE	Disease-oriented factors	Anger/bitterness/	<p><i>....”sometimes some of their siblings would be HIV negative so then, they would say uhh I would be bitter about my parents even those siblings so that bitterness would actually drive them not to take their medications.”</i></p> <p><i>...”some would say disclosure would not have been done fully to them by the parents, like they would be told medication you are taking is for headache, for you not to have a headache for the rest of your life you have to take the medication so if the adolescent doesn’t feel a headache so they attempt to stop”...</i></p> <p><i>.... “Also, some felt you know um let down by not being told the truth and just that anger” ...</i></p>
		Frustration/hopelessness factors	Suicidal thoughts/ Unmotivated	<p><i>...”Some of them they have suicidal attempts, so they just feel, what if I stop it and I die, because they... some of them are hopeless, they feel they have lost their self-esteem”...</i></p>
4.			Treatment fatigue	<p><i>....”I’ve felt that treatment fatigue is something, and it’s not surprising you know if you’re diagnosed with HIV since you were 4, you’ve been taking your tablets”...</i></p>

4.	MEDICATION BARRIERS TO TREATMENT ADHERENCE	Treatment regimen factors		<i>Because you've been doing it for so long and you're like I'm done! Sometimes it's just I don't wanna do it anymore"....</i>
		Pill factors	Pill size	<i>..."Also, the number of pills uhh and the even the size the size of some complain that ahh they're too big I can't swallow them</i>
			Pill number	<i>..."Know the pill burden, even if it's one pill you know it's like you've to take it every day, . They just feel fed-up they just say I've had enough</i>
			Pill side effects	<i>..."Issue of side effects... they will also give up on treatment because they can't cope. It's too much on them</i>

